NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE Guideline NG93

Learning disabilities and behaviour that challenges: service design and delivery

March 2018

Contents

Update information

Minor changes since publication

October 2019: the definition of behaviour that challenges has been amended to say that it can deny access to services. The definition also appears in the introduction.

This guideline is dedicated to the memory of Gary Bye. Gary approached his work as a Guideline Committee member with the same deep understanding and humanity as characterised his life-long work with people with learning disabilities and their families.

Introduction

The Department of Health asked NICE to produce this guideline on learning disabilities and behaviour that challenges: service design and delivery (see the scope).

This guideline covers services for people with a learning disability and behaviour that challenges, and their family members, carers and day to day support. It recommends providing a range of services, including specialist support, in the community to minimise the need for inpatient admissions. It also promotes a lifelong approach to supporting people which emphasises prevention and early intervention. Recommendations cover services for children, young people and adults across health and social care and education.

The guideline should be read alongside NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.

Background

An estimated 1.2 million children, young people and adults in England have a learning disability, and of these it is estimated that 10–17% display behaviour that challenges (Predictors, costs and characteristics of out of area placement for people with intellectual disability and challenging behaviour Allen et al. 2007). A more recent report suggested that there are over 40,000 children with learning disabilities who display behaviour that challenges (Estimating the number of children with learning disabilities in England whose behaviour challenges Emerson et al. 2014). In addition, approximately 1% of the adult population has an autism spectrum condition and 60–70% of these also have a learning disability (Estimating the prevalence of autism spectrum conditions in adults Brugha et al. 2012).

The most commonly used definition of behaviour that challenges is: 'behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to and use of ordinary community facilities' (Emerson et al. 1987[1]). Later definitions have highlighted the role of cultural context in determining whether behaviour is perceived as challenging (Emerson 1995[2]).

This guideline was developed in a context of changes to policy and practice for children, young people and adults with a learning disability (or autism and a learning disability) and behaviour that challenges. The support needs of these vulnerable groups were set out in 1992 in the Mansell report[3], which identified the need to invest in developing local services with appropriate levels of skilled staff to meet people's needs. This was restated in a later review, the so-called 'Mansell 2 report' (Services for people with learning disabilities and challenging behaviour or mental health needs Department of Health), which also highlighted the increased use of placements away from people's homes.

The exposure of widespread abuse at Winterbourne View hospital in 2011 led to a review of care provided in this hospital, and across England more widely, for people with a learning disability and behaviour that challenges. The resulting report Transforming care: a national response to Winterbourne View hospital (Department of Health) started a programme of work to improve services for people with a learning disability or autism who also have mental health conditions or behaviours described as challenging. In particular, this aimed to shift emphasis from inpatient care in mental health hospitals towards care based on people's individual needs and wishes and those of their families, provided by general and specialist services in the community. The programme did not meet its original targets, as highlighted in a report by the National Audit Office (Care services for people with learning disabilities and challenging behaviour), and was reconfigured in 2015.

The 'transforming care programme' is now led jointly by NHS England, the Association of Directors of Adult Social Services, the Care Quality Commission, Local Government Association, Health Education England and the Department of Health. The national plan Building the right support (2015) included plans for 48

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[1] Emerson E., Barrett S., Bell, C., Cummings R., McCool C., Toogood A., Mansell, J., (1987) Developing services for severe learning difficulties and challenging behaviours. Canterbury: Institute of Social and Applied Psychology. University of Kent

[2] Emerson E (1995) Challenging behaviour: Analysis and intervention in people with learning disabilities. Cambridge: Cambridge University Press

[3] Mansell Report (1992) Services for people with learning disabilities and challenging behaviour or mental health needs. Report of a project group (Chairman: Professor JL Mansell). HMSO, London.

‘transforming care partnerships’ to pilot new arrangements of services. The national plan was followed by NHS England’s national service model (October 2015) that set out the range of support that should be in place no later than March 2019. To support implementation of the interim service model, NHS England developed 3 Model service specifications (January 2017) and supplementary guidance on Developing support and services for children and young people with a learning disability, autism or both (September 2017). This guidance also supports the recommendations of Dame Christine Lenehan’s review (January 2017) on providing care and support for children and young people with complex needs who display challenging behaviour.

The aim of this guideline

This guideline takes into account the direction of travel in the transforming care programme. It aims to complement this work by providing evidence-based recommendations to support children, young people and adults with a learning disability (or autism and a learning disability) and behaviour that challenges to live their lives in the community like everyone else.

It is based on evidence about effectiveness and cost effectiveness of different support and services, and how those services are coordinated. It is also informed by the views of people who use services and their families on what is important to them in their care and support.

Who is it for?

- Commissioners and providers of health and social care services for children, young people and adults with learning disabilities and behaviour that challenges
- Health and social care practitioners working with children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers.

It is also relevant for:

- Children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers, including people who purchase their own care.

- Providers of related services, including housing, education, employment and criminal justice services.
- Practitioners working with children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers in other services or settings, including education, housing, voluntary and community services, employment, and criminal justice services

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government, and Northern Ireland Executive.

What is the status of this guidance?

The application of the recommendations in this guideline is not mandatory. Although there is no legal obligation to implement our guidance, health and social care practitioners, and practitioners in related services, are actively encouraged to follow our recommendations to help them deliver the highest-quality care.

How does it relate to legal duties and other guidance?

This guideline complements statutory duties and good practice as set out in relevant legislation and guidance. The recommendations cross-refer to legislation and other guidance where appropriate.

Relevant legislation and guidance includes:

- Accessible Information Standard
- Autism Act 2009
- Care Act 2014 and associated guidance
- Children Act 1989 and associated guidance
- Children and Families Act 2014
- Children and Young Peoples Act 2008
- Chronically Sick and Disabled Persons Act 1970
- Human Rights Act 1998
- Mental Health Act 1983, 2007
- Mental Capacity Act 2005 (amended 2007) and associated guidance on Deprivation of liberty safeguards.

How has it been developed?

The guideline has been developed by a Guideline Committee of people who use services; family members and carers of children, young people and adults with learning disabilities who display behaviour that challenges; and professionals. It has used information from an extensive review of research evidence, and from expert witnesses. The development followed the methods outlined in developing NICE guidelines: the manual and the Interim methods guide for developing service guidance (2014).

Equality and diversity issues have been considered throughout the development of the guideline. The committee also gave careful consideration to the potential resource impact of the recommendations.

1 Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

This guideline covers people of all ages with a learning disability and behaviour that challenges. All recommendations referring to ‘people with a learning disability’ relate to children, young people and adults unless specified otherwise.

Aims and principles

This guideline is based on the principle that children, young people and adults with a learning disability and behaviour that challenges should have the support they need to live where and how they want. It will help local areas shift their focus towards prevention and early intervention, enabling children, young people and adults to live in their communities, and increasing support for families and carers. This should reduce the need for people to move away from their home or community for care, education or treatment.

The guideline recommends ways of designing and delivering services that aim to:

- help people to have a good quality of life
- support people to have good physical and mental health and emotional wellbeing
- maximise people’s choice and control
- promote person-centred care and support
- help children, young people and adults take an active part in all aspects of daily life that they choose, based both on what they can do and what they want to do
- respect people’s cultural, religious and sexual identity
- identify when children, young people and adults are at risk of developing behaviour that challenges, so that support can be offered as early as possible

- promote continuity of relationships
- take a 'whole life' approach.

1.1 Achieving change: strategic planning and infrastructure

Local leadership

Recommendations for local authorities and clinical commissioning groups

1.1.1 Local authorities and clinical commissioning groups should jointly designate a lead commissioner to oversee strategic commissioning of health, social care and education services specifically for all children, young people and adults with a learning disability, including those who display, or are at risk of developing, behaviour that challenges.

1.1.2 Ensure that the lead commissioner:

- plans and oversees joined-up commissioning arrangements
- has in-depth knowledge and experience of working with children, young people and adults with a learning disability and behaviour that challenges, including knowledge of local services
- plans services that take a ‘whole life’ approach from early childhood onwards and enable smooth transitions.

Joint commissioning and funding

Recommendations for the lead commissioner (acting on behalf of local authorities and clinical commissioning groups)

1.1.3 The lead commissioner should ensure that budgets and other resources are pooled to develop local and regional services for children, young people and adults with a learning disability and behaviour that challenges. These should be pooled:

- across health, social care and education **and**
- with neighbouring authorities.

1.1.4 Consider jointly commissioning the most specialised behaviour support services across areas for children, young people and adults with particularly complex needs.

1.1.5 Ensure that funding mechanisms for service providers support creative and flexible community-based responses, for example, a contingency fund that service providers can draw on quickly if there is a crisis.

Planning and delivering services according to local need

Recommendations for the lead commissioner (acting on behalf of local authorities and clinical commissioning groups)

1.1.6 Ensure that service planning and delivery is based on an assessment of current and future service needs using:

- the local population prevalence of learning disabilities in children, young people and adults and the proportion who are likely to display behaviour that challenges
- an analysis of assessed needs in education, health and social care plans, to provide an early view of likely service needs and enable prevention and early intervention
- other sources of information, such as registers of people at risk of admission and other dynamic risk data; disabled children's registers; and records of referrals from liaison and diversion teams, youth offending teams and police.

1.1.7 Ensure that services are planned and delivered in a way that:

- is co-produced with children, young people and adults using services and their families, carers and independent advocates
- enables person-centred planning and provision
- addresses the needs of different age groups but also takes a 'whole life' approach to planning
- includes planning for a range of future housing and employment support needs
- integrates health, social care and other relevant services.

1.1.8 Develop local and regional plans that have a single care pathway and point of access for children, young people and adults with a learning disability and behaviour that challenges and their families and carers. Make sure this is reflected in local authorities' commissioning strategies and key documents such as the Market Position Statement.

For further information on how to develop care pathways, see organising effective care in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.

Managing risk

Recommendation for local authorities and clinical commissioning groups

1.1.9 Take joint responsibility with service providers and other organisations for managing risk when developing and delivering care and support for children, young people and adults with a learning disability and behaviour that challenges. Aim to manage risks and difficulties without resorting to changing placements or putting greater restrictions on the person.

Quality assurance

Recommendations for commissioners and service providers

1.1.10 Ensure services meet set service-level and individual outcomes, and that service providers show evidence of achieving these outcomes. This evidence could include:

- satisfaction and quality-of-life ratings of children, young people and adults who have used the service, and their family members, friends and carers
- outcomes measured by personalised and validated tools such as the 'measure of processes of care' (MPOC) tool, or the 'patient feedback questionnaire' (PFQ)
- a reduction in duration and frequency of behaviour that challenges
- stability of placements
- participation in education by children and young people
- reports on the use of restrictive interventions, including medication

- contact time with specialist professionals
- evidence from quality reviews and spot checking involving experts by experience
- quality checks by user-led organisations.

1.1.11 Inpatient services should provide the evidence in recommendation 1.1.10 in addition to evidence of detailed assessments, treatment outcomes and time to discharge.

1.1.12 Commissioners should establish a multi-agency group, including experts by experience and service providers, to monitor the quality of services and the outcomes achieved.

1.1.13 Service providers should use evidence gathered to continuously improve services. They should record the results and make them available to people who use services, and their families and carers.

1.1.14 Commissioners should make use of expertise from experts by experience to inform decision-making and quality assurance of services.

1.2 Enabling person-centred care and support

Involving people with a learning disability and behaviour that challenges

Recommendations for practitioners working with children, young people and adults and their families and carers

1.2.1 Practitioners working with children, young people and adults with a learning disability and behaviour that challenges, and their family members and carers, should get to know the person they support and find out what they want from their lives, not just what they want from services.

For more information on involving people in their care and support see working with people with a learning disability and behaviour that challenges, and their families and carers in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.

1.2.2 Actively involve people with a learning disability in all decisions that affect them. If a person aged 16 or over lacks the capacity to make a decision, staff must follow the Mental Capacity Act 2005.

1.2.3 Assess whether a child or young person under the age of 16 is Gillick competent and work in partnership with all children and young people. Include them in decisions about their treatment and ask them how they would like their families or carers to be involved.

1.2.4 Involve families, friends, carers or independent advocates if this is what the person wants, or where decisions are made in the best interests of a person aged over 16 in line with the Mental Capacity Act 2005. This should be done unless there is a compelling reason not to (for example, if there are safeguarding concerns).

1.2.5 Support children, young people and adults with a learning disability and behaviour that challenges to live where and how they want. Give them support that:

- is person-centred, reflecting their individual needs and choices and maximising their control
- helps them take an active part in all aspects of daily life that they choose, based both on what they can do and what they want to do
- takes into account the severity of their learning disability; their developmental stage; any communication difficulties or physical or mental health problems; and their life history
- respects their cultural, religious and sexual identity
- helps them before problems occur or as soon as they emerge, not just when crisis has been reached
- encourages people to speak out if they have any worries
- promotes continuity of relationships.

1.2.6 Find out children, young people and adults' information and communication needs, record them and share this information with everyone working with them in line with the Accessible Information Standard.

Recommendation for commissioners and practitioners working with children, young people and adults

1.2.7 Ensure that people with a learning disability and behaviour that challenges have access to speech and language therapy when they need it.

Advocacy

Recommendations for local authorities

1.2.8 Consider providing access to independent advocacy whenever it is wanted or needed by a person with a learning disability and behaviour that challenges. As a minimum, it must be offered by local authorities as described in the Care Act 2014, Mental Capacity Act 2005 and Mental Health Act 2007.

1.2.9 Ensure that independent advocates working with children, young people and adults with a learning disability and behaviour that challenges have skills and experience in working with these groups, and in working with specialist learning disability services.

See also recommendations 1.8.3 and 1.8.4 on independent advocacy in relation to inpatient admissions.

Coordinating care and support

Recommendations for local authorities, clinical commissioning groups and service providers

1.2.10 Local authorities working in partnership with healthcare professionals should assign a single practitioner, for example, a social worker (in a disabled children's team or community learning disability team) or community psychiatric nurse, to be the person's 'named worker'. The named worker should get to know the person and coordinate support to meet their needs over the long term.

1.2.11 The local authority, clinical commissioning group and service providers should liaise regularly with the named worker, keeping them informed and involved in decision-making.

Recommendations for the named worker

1.2.12 Arrange regular meetings to discuss the person's care and support and invite people in their support network, including family members, carers, independent advocates and practitioners from all services that support them. This could build on existing processes, for example, the education, health and care planning and review process for children (see Gov.uk's children with special educational needs and disabilities).

1.2.13 Recognise and use the expertise brought by all members of the person's support network (not only those who are paid).

Care and support planning

Recommendations for community learning disability teams and service providers

1.2.14 Community learning disability teams (or relevant children's services, for example disabled children's teams) and service providers should work in partnership with the child, young person or adult, their family members, carers and advocates and their named worker to develop, deliver and review their care and support plan. Develop a care plan that:

- meets the person's needs and preferences
- works to support and maximise the person's mental capacity
- takes into account people's fluctuating mental capacity and needs
- adopts a 'whole life' approach that covers what they want to achieve in both the short and long term, and supports smooth transitions
- takes a positive approach to managing risk
- sets out what to do to prevent or respond to a crisis.

1.2.15 Service providers and agencies responsible for commissioning and planning services (including specialist services) should match the specific skills of staff to the characteristics of the person with a learning disability and behaviour that challenges. Do this as soon as care and support planning begins.

1.2.16 Community learning disability teams or relevant children's services (for example, disabled children's teams) and service providers should review children, young people and adults' care and support with their named worker:

- according to timings agreed in their plan **and**
- whenever there is a significant change, for example, if the person is placed out of area.

1.2.17 When reviewing plans:

- involve people as set out in recommendations 1.2.1 to 1.2.4
- take account of people's fluctuating mental capacity
- check that staff are following the behaviour support plan recommendations in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions
- think about plans for the future, including whether changes might be needed to the person's housing or support.

1.2.18 As soon as a child, young person or adult develops behaviour that challenges, community learning disability teams (or relevant children's services, for example, child and adolescent mental health learning disability teams) and service providers should offer to work with them and their family or carers to develop a behaviour support plan.

For more information on what this should include, see the recommendations on behaviour support plan in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.

Supporting people to use personal budgets

Recommendations for local authorities and clinical commissioning groups

1.2.19 Ensure that a range of funding arrangements are available, including direct payments, personal budgets or individual service funds, depending on children, young people and adults' needs and preferences.

1.2.20 Offer people a choice of funding arrangements (see recommendation 1.2.19) and support people to use these budgets, where they wish to, by:

- telling them how each element of their support will be funded
- telling them how much money is available and how much control they have over how the money is spent
- giving them and their families and carers information about different ways of managing their budgets, and how these may affect their carer
- supporting them to try out different mechanisms for managing their budget
- offering information, advice and support to people who pay for or arrange their own care and support, as well as to those whose care and support is publicly funded
- offering information about benefits entitlement
- ensuring that carers' needs are taken fully into account.

[This recommendation is adapted from NICE's guideline on older people with social care needs and multiple long-term conditions.]

Delivering care and support

Recommendations for staff in all settings

1.2.21 In all settings, staff working with children, young people and adults with a learning disability, and their families and carers, should aim to reduce the risk of behaviour that challenges developing by:

- identifying health or sensory problems early
- providing strategies and interventions to support communication.

Follow recommendations on psychological and environmental interventions in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.

1.2.22 For people taking medicines:

- follow recommendations in NICE's guideline on managing medicines for adults receiving social care in the community **and**
- if the reason for the medicine relates to the person's behaviour or mental health, ensure it is reviewed regularly in line with recommendations on medication in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions, and recommendations in mental health problems in people with learning disabilities: prevention, assessment and management.

1.2.23 Ensure that children, young people and adults with a learning disability and behaviour that challenges know about and are able to use services to support their health and wellbeing. These should include:

- services helping people to make and maintain friends, relationships and social networks in their community and take part in community activities
- access to employment and pre-employment opportunities
- day opportunities where activities can be tailored to the person's interests, preferences, strengths and abilities
- universal healthcare services and health checks
- peer support opportunities.

1.3 Early intervention and support for families and carers

See section 1.6 for more recommendations on services for children and young people.

Recommendations for local authorities

1.3.1 Ensure that families and carers of children, young people and adults with a learning disability and behaviour that challenges are given support that helps them to:

- manage their role as carers
- care for the person and meet their needs, in relation to behaviour, care and support, communication, physical health, mental health, educational needs or any offending behaviour
- access support from specialist services when needed.

1.3.2 Provide information, guidance and ongoing support for families and carers of children, young people and adults with a learning disability and behaviour that challenges, which address different aspects of their life. Sources of support could include:

- peer support
- parent and carer groups or forums
- email support
- individual phone and face-to-face support
- family networks
- independent advocacy
- managed email networks (a shared discussion forum)
- social media groups.

1.3.3 Give family members and carers information in line with support and interventions for family members or carers in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions. This could be in the form of a 'welcome pack'. Provide this information:

- at the first point of contact with families
- through the local authority website, local libraries and universal services such as GP surgeries.

Recommendations for the named worker

1.3.4 Help people and their families to understand information about available support (see recommendation 1.3.3) from first contact onwards.

1.3.5 Advise family members and carers how to access:

- short break services
- specialist behaviour support
- training as set out in recommendations 1.7.1 and 1.7.2 in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.
- support in an emergency
- community resources, including voluntary organisations, networks and support groups
- local safeguarding procedures, including how to raise safeguarding concerns or make a complaint.

1.3.6 Ensure that family members and carers have information such as contact details of staff and key dates and appointments.

1.4 Services in the community – prevention, early intervention and response

Developing services in the community

Recommendations for the lead commissioner (acting on behalf of local authorities and clinical commissioning groups)

1.4.1 The lead commissioner should commission services in the community for people with a learning disability and behaviour that challenges (including for people in contact with, or at risk of contact with, the criminal justice system). These services:

- should be able to cater for lower-level needs up to intensive, complex or fluctuating needs
- could be set up either as 1 large team with different subteams or as several separate teams
- should be provided wherever possible as an alternative to, and to reduce the potential need for:
  - inpatient care for children, young people and adults or
  - residential placements for children and young people.

1.4.2 Services in the community should fulfil the following core functions:

- specialist prevention and early intervention
- developing capacity in non-specialist community services to prevent unnecessary inpatient admissions
- giving support and training to families and carers (by following the recommendations on support and interventions for family members or carers in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions)
- quality assurance and service development
- short-term assessment and intervention
- longer-term complex intervention
- crisis response and intervention.

1.4.3 Ensure that children, young people and adults with a learning disability can get specialist support through their community learning disability team that meets their needs, for example, in relation to:

- behaviour
- communication
- social care and support needs
- physical health
- mental health
- education
- offending behaviour.

This could be achieved by employing relevant practitioners within the community learning disability team or by developing close links with practitioners in other relevant services.

Recommendations for community learning disability teams and service providers

1.4.4 Services who provide support through the community learning disability team should work together and provide consultancy and support to each other. They should work with children, young people and adults, and their family members and carers, in a way that is:

- personalised
- flexible
- responsive
- accessible
- reflective.

1.4.5 If a child, young person or adult develops, or is at risk of developing, offending behaviour, community learning disability teams should refer them to appropriate specialists, such as community forensic or youth justice services, as soon as possible (see recommendations 1.4.12 to 1.4.16). These services should:

- provide evidence-based early interventions that are adapted for people with a learning disability and address the specific behaviour
- work in an ongoing partnership with each other and with the community learning disability team whenever needed.

1.4.6 Community learning disability teams should maintain good communication and links with the police and liaison and diversion teams so that:

- they can advise on assessments of vulnerability, particularly for people with mild or borderline learning disabilities who may otherwise not be identified as vulnerable
- people who need support can be diverted from the criminal justice service to community learning disability teams.

Specialist behavioural support

Recommendations for the lead commissioner (acting on behalf of local authorities and clinical commissioning groups)

1.4.7 Ensure that specialist assessment and behavioural support are available in the community so that children, young people and adults can stay where they currently live and avoid moving.

1.4.8 Ensure that specialist services for behaviour that challenges are available to everyone with a learning disability and behaviour that challenges, based on an assessment of each person's need and risk and taking into account the benefit of early intervention.

1.4.9 The lead commissioner should:

- set local maximum waiting times for initial assessment, and for urgent and routine access to treatment and support
- ensure that waiting times for specialist behavioural support do not exceed NHS waiting time standards.

Intensive behavioural support during a crisis

Recommendations for local authorities, clinical commissioning groups, community learning disability teams and specialist services

1.4.10 Provide a local, personalised response to children, young people and adults who need intensive support during a crisis. This response should:

- focus on keeping people in their own home
- have an out-of-hours helpline as a first option with the capacity to respond rapidly (within 1 hour or in line with local mental health crisis response times), staffed by people with skills and knowledge in learning disabilities and behaviour that challenges, and specialist skills in mental health problems
- provide face-to-face support within 4 hours if needed, based on initial triage
- involve partnership with other commissioners, service providers and family members and carers
- include giving staff access to the person's information if they are already in contact with services
- provide short-term support to achieve aims that are agreed with the person
- include clear contact details for children's services (as set out in the Local Offer) and adults' services.

1.4.11 Use a clear, coordinated approach to reducing the level of support from more intensive services in line with the person's needs. Learn from what happened and use this knowledge to inform future early intervention and prevention services and support crisis plans.

Services for people in contact with, or at risk of contact with, the criminal justice system

Recommendation for local authorities and clinical commissioning groups

1.4.12 Commission local community forensic services for children, young people and adults with a learning disability and behaviour that challenges who are in contact with, or at risk of contact with, the criminal justice system to prevent out-of-area hospital placement. These could be provided as stand-alone teams, or as a specialism within an existing team, for example, a community learning disability team, or a learning disability specialism within a community forensic team.

Recommendations for service providers, including forensic services

1.4.13 When forensic community learning disability services are supporting children, young people and adults with a learning disability (for example, if they are subject to a forensic community rehabilitation order or a community treatment order), they should enable them to live in the community, as close to home as possible, and in the least restrictive setting.

1.4.14 Forensic community learning disability services should stay in frequent contact with the person they are supporting, including those who are in out-of-area placements or criminal justice settings, and help them build and maintain social links in their community.

1.4.15 Forensic learning disability services and probation services should work together to agree who is best able to support the person in meeting the requirements of their treatment or rehabilitation order.

1.4.16 Forensic learning disability services, mental health, specialist voluntary sector organisations, learning disability services and social care services should establish care pathways and close links with each other to help them refer people quickly between these services to get the right support and effectively manage risk.

1.5 Housing and related support

Giving people a choice of housing

Recommendations for local authorities, clinical commissioning groups and service providers

1.5.1 Commissioners should work with local housing and social care providers to identify the specific housing needs of adults with a learning disability and behaviour that challenges. They should ensure areas have a range of housing and care options available that meet these needs and cater for different preferences and person-centred support needs (see also section 1.2).

1.5.2 Enable adults to live close to their family, friends and community unless they choose not to or there is a compelling reason not to.

1.5.3 Where possible ensure that, wherever people live, they have security of tenure in line with the Real Tenancy Test.

1.5.4 When helping adults with a learning disability and behaviour that challenges choose where to live:

- provide information on the range of possible options
- take into account their preferences and any specific support needs or risks, including the impact of environmental factors on the person (see the recommendation on environmental factors in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions)
- give them advice on adapting their current home if needed.

1.5.5 Offer people the option to live alone with appropriate support if they prefer this and it is suitable for them.

1.5.6 If adults prefer not to live alone with support, or it is not suitable for them, offer them the option of living with a small number of other people in shared housing that has a small-scale domestic feel. Involve people in choosing how many people, and who, they live with.

1.5.7 Offer adults housing outside their local community only:

- if it is what the person wants
- if it is indicated after a full assessment and planning process, which takes into account the person's preferences, needs and risks
- for a specified time that has been agreed with the person, or agreed in their best interests if they lack capacity to decide this – for example, if they are in crisis and there is no local placement available.

1.5.8 If someone is moving outside their local area, local authorities, clinical commissioning groups and commissioners should:

- establish the commissioner who is responsible for paying for the person's care and support
- ensure they will still have the support they need
- make a plan that enables them to return to their local area if they want to, or if it is in their best interests if they lack capacity to decide this.

1.6 Services for children and young people

Recommendations for local authorities, clinical commissioning groups and the lead commissioner

1.6.1 Local authorities should ensure that parents and carers of children and young people with a learning disability and behaviour that challenges have support to care for their child (see section 1.3).

1.6.2 Local authorities must promote the upbringing of children and young people with a learning disability and behaviour that challenges by their families, in line with section 17 of the Children Act 1989. This should include providing a range of services including education, and general and specialist learning disability support services in the community, as an alternative to residential placements away from home and to reduce the potential need for such placements.

1.6.3 The lead commissioner should ensure that specialist behavioural support in the community for children and young people includes support from education and child and adolescent mental health service (CAMHS) practitioners who have skills and experience in working with children and young people with a learning disability and behaviour that challenges.

Recommendations for local authorities, service providers and practitioners

1.6.4 Health, mental health and behaviour support practitioners should work with other services, for example, education and social care, to:

- deliver the outcomes agreed in a child or young person's education, health and care plan
- provide support and interventions in line with NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions
- maximise life opportunities for children and young people, including by ensuring they have access to meaningful education
- support smooth transitions between services in line with organising effective care in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions
- support children and young people to develop skills for independence
- take a positive approach to managing risk.

This applies to children and young people in residential placements, as well as those living at home.

1.6.5 If a child or young person's behaviour that challenges is deteriorating or causing concern, the local authority should carry out a multi-agency review of their education, health and care plan (or other relevant plan) and involve the child or young person and their parents or carers. Review whether the plan needs to be updated and additional support provided if the child or young person's needs have changed.

Exploring alternatives to residential placements for children and young people

Recommendations for the lead commissioner, service providers and practitioners

1.6.6 Support parents and carers to understand the full range of options for education, care and support for their child.

1.6.7 When considering a residential placement, arrange a multi-agency review to explore all options and to review the child or young person's education, health and care plan. Include in this discussion:

- the child or young person, and their parents or carers
- the lead commissioner on behalf of the local authority and clinical commissioning group
- at least 1 practitioner with clinical expertise in learning disability and the specific behaviour that is challenging
- an independent expert by experience
- special educational needs staff, or staff from their school or college.

1.6.8 Only offer children and young people a residential placement:

- if assessment and care planning show that their needs (including their educational needs) cannot be met while they are living at home, and all alternatives to residential care have been considered and exhausted, **or**
- following a request by the child or young person's family, which has been considered under the Children and Families Act 2014.

Living in residential placements

Recommendations for local authorities, clinical commissioning groups and service providers

1.6.9 Commission residential placements for children and young people as close to home as possible. Take into account in local authority contracts that some families may need financial support to help them see their child and for their child to visit them.

1.6.10 Support children and young people to maintain links with their family, friends and community (for example, members of their religious community) while they are in a residential placement.

1.6.11 Local authorities and service providers must promote maximum contact between children and young people living in residential placements and their family members and carers (in line with schedule 2 of the Children Act 1989). If a placement lasts longer than 3 months, the Visiting Regulations 2011 must be followed, for both local and out-of-area placements. Help families stay in touch between visits, for example using Skype.

Planning and review to support children and young people leaving a residential placement

Recommendations for local authorities, clinical commissioning groups and practitioners

1.6.12 As soon as a child or young person moves into a residential placement, local authorities and clinical commissioning groups should ensure that:

- a plan is developed for how they will progress towards returning to their family home, if appropriate, and towards greater independence
- they continue to be supported to meet the outcomes identified in their education, health and care plan.

1.6.13 Review the plan in recommendation 1.6.12 at least every 6 months to check that progress is being made. This could be done as part of a looked-after child review, an education, health and care plan review, or sooner if needed.

1.6.14 Plans should be reviewed by the practitioner responsible for overseeing the child or young person's education health and care plan and all other practitioners involved in their care and support, including a specialist in behaviour that challenges.

1.6.15 If progress towards the outcomes in the plan has not been made, explore and address the reasons for this. If the child, young person or their family disagrees with the decision made at the review meeting, explain how they can challenge the decision if they want to.

1.7 Short break services

Recommendations for local authorities, commissioners and service providers

1.7.1 Local authorities must, in line with the Breaks for Carers of Disabled Children Regulations 2011 and the Children and Families Act 2014:

- provide a range of short breaks for children and young people with a learning disability and behaviour that challenges **and**
- publish as part of their Local Offer a statement of the range of services available and how eligibility will be assessed.

1.7.2 Commissioners in health and social care should provide sufficient, reliable, flexible and varied short break options, including both breaks away and support at home, for adults with a learning disability and behaviour that challenges.

1.7.3 Ensure that short breaks are:

- community-based and close to home
- available based on need, and at short notice both in crisis and to prevent a crisis
- tailored to the needs of the person and their family or carers, taking into account the person's interests and preferences
- able to provide a positive experience for the person being supported
- able to deliver what is agreed in the education, health and care plan or care and support plan; carer's assessment; or behaviour support plan
- planned in advance wherever possible and involve people and their family members and carers visiting the service first to see if it is suitable and to get to know the staff providing it

- provided by staff who understand and respect people's cultural norms and values and their choices about personal care, private life and lifestyle.

1.8 Making the right use of inpatient services

Exploring alternatives to inpatient admission

Recommendations for commissioners, service providers and practitioners

1.8.1 Admit children, young people and adults with a learning disability and behaviour that challenges to inpatient units only if assessment and care planning show that their needs cannot be met safely in the community, and all possibilities for doing so have been considered and exhausted.

1.8.2 When thinking about inpatient admission, arrange a discussion to explore all other viable options. Include in this discussion:

- the person and their family members and carers
- at least 1 practitioner with clinical expertise in learning disability and the specific behaviour that is challenging
- at least 1 independent expert by experience.

For further guidance, see NHS England's information on community Care and treatment reviews or, for children and young people, community Care, education and treatment reviews.

Providing information

Recommendations for local authorities, clinical commissioning groups and service providers

1.8.3 When there is a possibility that someone will be admitted to hospital, including as an informal admission, local authorities and clinical commissioning groups should give them and their family and carers accessible, independent information and advice about their rights, access to independent advocacy and other possible options for treatment, and care and support.

1.8.4 Service providers must provide information about independent mental health advocacy as required by the Mental Health Act 1983.

When a placement is needed

Recommendation for local authorities and clinical commissioning groups

1.8.5 Provide an inpatient placement that is as close as possible to where the person usually lives.

Recommendations for inpatient services and community learning disability teams, including the named worker

1.8.6 The named worker should support the person to maintain links with their family, friends and community (for example, members of their religious community) while they are in hospital, and give their family and friends information about their progress.

1.8.7 If people are admitted as inpatients outside their local area, social workers in the community learning disability team and the named worker should stay in contact with the person, and help them stay in contact with other key practitioners in their own area.

1.8.8 When someone is admitted as an inpatient, offer them interventions in line with recommended psychological and environmental interventions in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions. Ensure that these interventions specifically address their needs and the reason for their admission.

Planning and review to support discharge

Recommendations for inpatient services and community learning disability teams

1.8.9 As soon as the person is admitted, the hospital and community learning disability team should work together to develop a discharge plan.

1.8.10 Practitioners involved in the child, young person or adult's care and support should review the person's discharge plan at least every 3 months. Include in these reviews:

- the person and their family members or carers
- the practitioner responsible for agreeing discharge
- a specialist in behaviour that challenges.

1.8.11 Think about using the Care and treatment review process or Care programme approach as a framework for reviews to support discharge for adults. For children and young people think about using the Care, education and treatment review or education, health and care planning process.

1.8.12 If the person is not discharged after the meeting with practitioners involved in their care and support, provide sufficient reason for this and develop a new plan towards discharge. Explain to the person and their family or carers how they can challenge the decision if they want to.

1.8.13 Tell people who might apply to, or are referred for, a first-tier mental health tribunal relating to being an inpatient, about their right to request an independent clinician (in line with section 76 of the Mental Health Act 1983) to:

- visit them at any reasonable time and examine them in private
- inspect any records relating to their conditions and treatment.

1.9 Staff skills and values

Recommendations for commissioners, local authorities and service providers

1.9.1 As part of staff recruitment and training, ensure that staff have the skills, knowledge and qualities they need to support the children, young people and adults they are working with. This includes:

- the skills and knowledge recommended in staff training, supervision and support in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.
- being resilient and compassionate
- showing that they care
- understanding and respecting the person's human rights, faith, culture, identity and values.

1.9.2 Ensure that staff providing direct support to children, young people and adults with a learning disability and behaviour that challenges have the 'direct contact' level competencies of the Positive Behavioural Support Academy's Positive behaviour support competence framework.

1.9.3 Give staff providing direct support access to advice from behaviour support specialists with 'consultant' level competencies of the Positive Behavioural Support Academy's Positive behaviour support competence framework.

1.9.4 Local authorities and clinical commissioning groups should plan for and resource training among service providers who provide day-to-day support about how to work with young people and adults with a learning disability who are at risk of offending.

1.9.5 Organisations should ensure that staff have supervision and support, in line with the recommendations on staff training, supervision and support in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.

1.9.6 Involve young people and adults with a learning disability and behaviour that challenges in staff recruitment. Involve their family members and carers too if the person agrees, unless there is a compelling reason not to.

1.9.7 Think about how to involve children with a learning disability in staff recruitment.

Terms used in this guideline

The Think Local, Act Personal care and support jargon buster explains many of the social care terms used in this guideline.

Adult

In this guideline, ‘adults’ are aged 18 years or older.

Behaviour support specialist

A practitioner who has training in helping people and their family members and carers to understand and change their behaviour if it is causing problems for them.

Behaviour that challenges

Behaviour of such an intensity, frequency or duration that the physical safety of the person, or others around them, is likely to be placed in serious jeopardy. It also includes behaviour that is likely to severely limit or deny access to and use of ordinary community facilities.

Carer

Someone who provides informal care and support to a child, young person or adult with a learning disability. It does not cover staff who are paid to provide care or support.

Children

In this guideline, ‘children’ are aged 12 years or younger.

Contingency fund

A sum of money set aside to fund any unforeseen expenditure, and to respond quickly in an emergency.

Experts by experience

People with lived experience of using services, including people with a learning disability themselves and their family members and carers.

Forensic services

Specialist services that work with people in contact with, or at risk of contact with, the criminal justice system.

Lead commissioner

A commissioner appointed by the local authority and clinical commissioning group who oversees strategic joint commissioning arrangements for health, social care and education services specifically for all children, young people and adults with a learning disability, including those who display, or are at risk of developing, behaviour that challenges.

Learning disability

In line with NICE's guideline on challenging behaviour and learning disabilities, a learning disability is defined as meeting 3 core criteria:

- lower intellectual ability (usually an IQ of less than 70)
- significant impairment of social or adaptive functioning
- onset in childhood.

- A person's learning disability may be described as mild, moderate, severe or profound. Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability.

Positive behaviour support

Positive behavioural support is a person-centred approach that uses a multi-element format to better understand and so reduce behaviour that challenges. It can include changing the person’s environment, developing their skills, providing focused support and developing reactive strategies.

Real Tenancy Test

The Real Tenancy Test is a quick test to check that a person who lives in supported accommodation enjoys the same rights and protections in law as a person who has a full tenancy agreement for their rented home.

Residential placement

Examples of residential placements include residential care homes for adults and, for children and young people, placements that involve living away from their family home, for example, in residential schools and colleges.

Service providers

This can be any organisation in the public, private or voluntary sector that offers a service to people with a learning disability and behaviour that challenges. This can include services such as hospitals, care homes and organisations that provide support for people to live in their own homes or with their family.

Short breaks

Also known as respite care, these involve a person with care and support needs spending regular short periods away from their main carer, to give the carer a break and the person a chance to do something different. These breaks may take place in the person's own home, in the home of an approved carer or in a residential placement.

Young people

In this guideline, ‘young people’ are aged 13 to 17 years.

2 Research recommendations

The Guideline Committee has made the following recommendations for research.

2.1 Models of person-centred support

Research question

What models of delivering person-centred support are effective and cost effective for people with a learning disability and behaviour that challenges, and their family members and carers?

What are the views and experiences of people with a learning disability and behaviour that challenges and their family members and carers, of different models of delivering person-centred support?

Why this is important

Person-centred support is the current recommended approach and is at the centre of this service guideline. However, there is little published research about what configurations of services and resources provide the best person-centred support for people with a learning disability and behaviour that challenges, and their families and carers. There is also limited research from the point of view of people with a learning disability and their families and carers on what good person-centred support looks like, how it can be measured or benchmarked or what it means for them.

Criterion	**Explanation**
Population	Children, young people and adults with a learning disability and behaviour that challenges, and their family members and carers
Intervention	Models, approaches, configurations of services and resources for delivering person-centred support
Comparators	Service as usual or alternative models or approaches for delivering person-centred support
Outcomes	Acceptability of the model/approach to people who use services Health and social care related quality of life Service user involvement in planning Availability, access and uptake of local services Equity of access; Meeting complex, physical and mental health needs; Level and type of support from care workers and carers. Costs and resource use

Study design	Robust comparative evaluations including randomised controlled trials (RCTs), non-randomised controlled trials, and prospective cohort studies which determines the relative effectiveness of different approaches to delivering person-centred support Qualitative studies of the views and experiences of people who use services
Timeframe	No specific timeframe required.

2.2 Supporting family members, carers and staff

Research question

What types of services or approaches are effective in supporting family members, carers and staff to be resilient and able to provide care and support to people with a learning disability and behaviour that challenges?

Why this is important

Enabling family members, carers and staff to provide continuing care and support can help prevent placements from breaking down, which can lead to out-of-area placements. Investment in carers, support networks, initiatives that support independent living, and community networks are key to helping people develop greater resilience. This is especially important if new approaches to service delivery, such as personalisation, are to succeed. However, there is no direct empirical evidence of the social and economic benefits associated with investment in such approaches and services.

Criterion	Explanation
Population	Family members, carers and staff that provide support to people with learning disabilities and behaviour that challenges
Intervention	Methods and approaches for supporting staff, carers and families to be resilient and able to provide care and support, including support networks, access to specialist professionals, whole family approaches, home based support, respite, staff training and others.
Comparators	Service as usual or alternative models or approaches for delivering support including support networks, access to specialist professionals, whole family approaches, home based support, respite, staff training and others.
Outcomes	Continuity of care Families and carers stress and resilience

	Staff stress and resilience Health and social care related quality of life Costs and resource use
Study design	Studies using a comparative design such as randomised controlled trials (RCTs), non-randomised controlled trials, and prospective cohort studies which determines the relative effectiveness of different interventions or approaches to deliver support. Qualitative studies of the views and experiences of people who use services.
Timeframe	No specific timeframe required.

2.3 Models of supported living

Research questions

What is the effectiveness and cost effectiveness of models of shared, supported living, such as Shared Lives?

What are the views and experiences of people sharing their home and people who live with them under programmes such as Shared Lives?

Why this is important

It is important that people with a learning disability and behaviour that challenges have more choice and control over where they live. Models of supported living, such as Shared Lives, are promising models for people with a learning disability. However, the support needs of people with a learning disability and behaviour that challenges are more complex and there is very limited evidence about which types of supported living are effective specifically for them. It would be useful to know what kinds of supported living are acceptable and feasible for people with a learning disability and behaviour that challenges, and their families, as well as for Shared Lives families.

Criterion	**Explanation**
Population	Young people and adults with a learning disability and behaviour that challenges, and their family members and the families and carers providing supported living options
Intervention	Models of supported living, such as Shared Lives
Comparators	Alternative models of shared living or current model of housing such as residential care or family home

Outcomes	Acceptability of the model/approach to people who use services and families/carers providing the service Health and social care related quality of life Availability, access and uptake of local services Meeting complex, physical and mental health needs; Level and type of support from care workers and carers; Service user satisfaction Costs and resource use
Study design	Studies using a comparative design such as randomised controlled trials (RCTs), non-randomised controlled trials, and prospective cohort studies which determines the relative effectiveness of different approaches to delivering supported living options. Qualitative studies of the views and experiences of people who use services and of the families and carers providing services.
Timeframe	No specific timeframe required.

2.4 *Effective components of integrated regional services for people with a learning disability and behaviour that challenges*

Research questions

What are the effective components of an integrated regional service for people with a learning disability and behaviour that challenges across health and social care (including pooling budgets and other resources)?

What are the barriers and facilitators to pooling budgets and other resources across regions?

Why this is important

The Winterbourne View Review Action Group and the Transforming Care programme recommended that health and social care services should pool budgets. However, reports from the National Audit Office highlight that there has been little evidence of this happening in practice. Research is needed to know what mechanisms enable or stop this practice from happening and whether the practice results in better outcomes for people with a learning disability.

Criterion	**Explanation**

Population	Children, young people and adults with a learning disability and behaviour that challenges, and their family members and carers
Intervention	Models, approaches, configurations of services and resources for delivering an integrated regional challenging behaviour service across health and social care including models led by different practitioners, different team structures, the components and configurations of models or services, the barriers and facilitators to the implementation of models and others.
Comparators	Service as usual or alternative models or approaches for delivering an integrated regional challenging behaviour service across health and social care
Outcomes	Change and improvement in service design and delivery Acceptability of the model/approach to people who use services Health and social care related quality of life Choice and control Service user involvement in planning Availability, access and uptake of local services Equity of access; Meeting complex, physical and mental health needs; Level and type of support from care workers and carers; Geographical variation in service provision (locally, regionally and nationally); Timely discharge Out of area placements Use of inpatient services
Study design	Studies using a comparative design such as randomised controlled trials (RCTs), non-randomised controlled trials, and prospective cohort studies which determines the relative effectiveness of different components of an integrated regional challenging behaviour service across health and social care. Qualitative research regarding barriers and facilitators to pooling budgets and other resources across regions for the purposes of service improvement
Timeframe	No specific timeframe required.

2.5 Factors associated with housing

Research questions

What is the acceptability and feasibility of different house size/ residency for people of different support needs?

What is the effectiveness and cost effectiveness of different household's sizes on incidence and severity of behaviour that challenges and quality of life for people with different support needs?

Why this is important

The evidence reviewed for this guideline suggests that people with learning disabilities and behaviour that challenges want to have choice about where they live and live in spaces that are 'homelike'. However, there is limited evidence about the acceptability, feasibility, effectiveness and cost effectiveness of different house size/ residency for people with different support needs. It is important that commissioners and service providers have high quality evidence to base housing investment decisions on and to ensure good outcomes for people living in different types of housing with different support needs

Criterion	**Explanation**
Population	Children, young people and adults with a learning disability and behaviour that challenges, and their family members and carers
Intervention	Different types of housing provision, such as congregate, non-congregate, cluster, dispersed, supported housing
Comparators	Alternative models of housing or current model of housing such as residential care or family home
Outcomes	Acceptability of the model/approach to people who use services Health and social care related quality of life Availability, access and uptake of local services Meeting complex, physical and mental health needs; Level and type of support from care workers and carers; Costs
Study design	Studies using a comparative design such as randomised controlled trials (RCTs), non-randomised controlled trials, and prospective cohort studies which determines the relative effectiveness and cost effectiveness of different housing options that consider the factors of housing size and differing levels of support. Qualitative studies of the views and experiences of people who use services about the acceptability and feasibility of different housing options
Timeframe	No specific timeframe required.

2.6 Workforce capacity and skills

Research questions

What skills and competencies deliver the best outcomes for people with behaviour that challenges including people in contact with, or who may have contact with, the criminal justice system in general and specialist services?

What configuration of skills and professional competencies in general and specialist services can deliver the best outcomes for people with a learning disability and behaviour that challenges services?

Why this is important

The evidence reviewed for this guideline suggests that when staff do not have the right knowledge and skills, this is bad for service delivery and it has a negative impact on service users. The evidence also suggests that people were often unhappy with how little expert knowledge staff had. This suggests that research is needed about what configuration of skills and professional competencies can deliver the best outcomes for people with behaviour that challenges. We do not currently know how many people each service needs and with what skills to meet the service demands. This is important because without the capacity and appropriate skills of the workforce in place, it won't be possible to deliver good outcomes for people using services.

Criterion	**Explanation**
Population	Children, young people and adults with a learning disability and behaviour that challenges, and their family members and carers Staff that provide support to people with learning disabilities and behaviour that challenges
Intervention	Particular configurations of staff skills and competencies
Comparators	Alternative configurations of staff skills and competencies or usual care
Outcomes	Continuity of care Health and social care related quality of life Acceptability of the model/configuration/approach to people who use services Frequency severity and duration of behaviour that challenges

	Meeting complex, physical and mental health needs of people with behaviour that challenges including people in contact with, or who may have contact with, the criminal justice system Level and type of support from care workers and carers Negative outcomes Staffing levels Staffing ratios Staff retention Organisational factors Environmental factors Costs and resource use
Study design	Studies determining the effectiveness and cost effectiveness of different staff configurations, their skills and competencies for people with differing levels of support. Qualitative studies of the views and experiences of people who use services about the acceptability and feasibility of different staff configurations, their skills and competencies for people with differing levels of support
Timeframe	No specific timeframe required.

2.7 Services across the lifespan

Research questions

What is the effectives and cost effectiveness of different resource allocation models of services over the lifespan for people with learning disabilities and behaviour that challenges?

Why this is important

Research reviews such as ‘From Cradle to the Grave’ (NIHR, 2004) and ‘Shaping our Future’ (NCCSDO, 2008) have highlighted the gaps in research about people with learning disabilities and their access to health services. We did not find review evidence that could tell us whether planning for potential service needs across the lifespan is more effective or cost effective than currently, and what the impact would be with different configurations of services.

The review work for this guideline found little evidence or data about what the appropriate capacity of different types of community based services needs to be to rebalance care into the community instead of inpatient and closure of inpatient beds as part of the Transforming care programme

Criterion	**Explanation**
Population	Children and young people with a learning disability and behaviour that challenges services
Intervention	Service planning and commissioning Resource allocation models
Comparators	No lifespan planning Alternative to lifespan planning
Outcomes	Costs and savings Child development outcomes Continuity of care Acceptability of the intervention to people who use services Health and social care related quality of life Availability, access and uptake of local services Equity of access; Uptake of services
Study design	Decision analytic modelling Economic evaluation
Timeframe	No specific timeframe required.

3 Evidence review and recommendations

This guideline was developed using the methods and processes set out in Developing NICE guidelines: the manual (2014) and the Interim methods guide for developing service guidance (2014). The nature of the guideline topic required some adaptation of these methods, to accommodate the volume and nature of the evidence. Methods were agreed with NICE during the process and are set out below. For more information on how this guideline was developed, see Appendix A.

Overview

For this guideline, we conducted 1 single comprehensive search, which encompassed all questions. This search strategy was not limited by study design or date at this stage. Additional sources of research literature were searched, including websites of charities and other relevant organisations, and published and unpublished work suggested by the Guideline Committee.

An additional search for assistive technology to support independent living was conducted. The Guideline Committee considered the link between environment and behaviour that challenges, and it was noted that person may no longer show behaviour that challenges if they were in the right home environment. The Guideline Committee considered the population as currently defined too narrow in this particular case. In the original search strategy search terms were combined for "people with learning disabilities" plus "behaviour that challenges". Therefore, to broaden the population to all people with learning disabilities, the search was re-run with the population search terms for "people with learning disabilities" and omitting the search terms for "behaviour that challenges". Search outputs were screened in the same way as the main search outputs.

Following NICE processes, an updated search was conducted at the end of the process to capture any new studies published since the first search. Any new studies were screened against the exclusion criteria and considered for any new or contradictory findings. Studies that were included in the review were checked for any more recent studies that had included it as a reference.

Documents that related to the Transforming Care programme were screened for references and added to the database of studies for screening against the exclusion criteria.

Further detail on this search is provided in Appendix A.

All results (n=25,374) were imported into EPPI-Reviewer 4, a software package developed to support systematic reviews. A de-duplication tool removed 6556 study entries as duplicates, leaving 18,818 studies, which were manually screened based on the title and abstract against the inclusion criteria defined in the review scope.

The exclusion criteria were as follows.

Exclude date – 2001: studies were excluded if they were published before the publication of the ‘Valuing People’ White Paper and the Health and Social Care Act 2001 to reflect the contemporary arrangements of health and social care services and views and experiences.

Exclude – not published in English: studies were excluded from this review if not published in English due to resource considerations. We did not exclude non-English language studies in the search strategy to ensure that any studies not published in English were still identified.

Exclude country: studies were excluded if they reported on services or views of experiences from countries with sufficiently different health and social care service systems to reduce the generalisability of their findings to the UK context. Studies were included if they were from OECD-Europe (including Austria, Belgium, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Luxembourg, the Netherlands, Norway, Poland, Portugal, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, Turkey and United Kingdom), Canada, Australia and New Zealand.

Exclude population: studies were excluded if they did not include people with learning disabilities and also behaviour that challenges.

Exclude intervention: studies were excluded if they were not about services or interventions to treat, prevent or manage behaviour that challenges as defined in the scope of the clinical guideline.

Workforce: studies were excluded if the topic was exclusively about the qualifications, training and education of staff who work with people with learning disabilities and behaviour that challenges without reference to any impact on services.

Exclude policy and guidance: studies were excluded if they were documents produced for policy or guidance without any empirical research evidence.

Exclude evidence type: studies were excluded if evidence was not derived from primary research. Examples include opinion pieces, discussions, essays, trade journal articles and dissertations.

Exclude study is in a systematic review: study is a primary study already reviewed in an included systematic review

To ensure consistency in screening against the exclusion criteria two reviewers coded a 10% sample of studies independently of each other. Discrepancies were discussed and resolved and where no agreement could be reached were resolved by a third reviewer. Coding instructions for the exclusion criteria were further refined.

Systematic reviews findings were included where at least 80% of the included studies in the review met our inclusion criteria. Systematic reviews that did not meet this criteria were screened for any potentially relevant studies in the reference list. Any studies meeting the inclusion criteria were retrieved and screened against the inclusion criteria on the full text. Primary studies that were identified that were also reviewed in an included systematic review were excluded to avoid double counting findings.

We found 3 good quality systematic reviews of people's views and experiences for both people who accessed services and their families and carers. These systematic reviews were presented as the first set of evidence as they addressed themes that were relevant across all the review questions and identified potential gaps in studies of views and experiences. The review team worked with the Guideline Committee to develop review protocols specific for each question – this defined the Population, Intervention, Comparator and Outcomes (PICO) and the types of studies best suited to answer the question.

Studies that were included after the initial screening stage were assigned to questions. Full texts were retrieved for studies included at this stage, and screened again against criteria defined in the protocol specific to each review question.

Included studies were rated for internal validity (the extent to which the study can measure what it aims to measure) and external validity (the generalisability of the study findings to the population in the guideline scope) using critical appraisal checklists adapted from the NICE manual (and agreed with NICE) and the results tabulated. Different checklists were used for different study designs as appropriate (see Appendix B for further details). The checklist for each type of study design considered the rigorousness of execution, the strength and limitations of the study designs, and efforts to minimise bias in the findings. Studies were rated for internal and external validity using ++/+/- (meaning high, moderate and low). The 2 ratings were then combined in to a single rating, which was weighted towards internal validity as shown in the table below (that is, the combined quality rating could not be higher than the internal validity score).

Internal validity	External validity	Combined quality rating	Overall quality rating
-	-	-	Low
+	-	+	Moderate
++	-	+	Moderate
-	+	-	Low
+	+	+	Moderate
++	+	+	Moderate
-	++	+	Moderate
+	++	+	Moderate
++	++	++	High

The evidence tables (Appendix B) provide details on each included study: information about the study's focus and context, design and findings, as well as details on critical appraisal, which underpins the overall quality ratings.

For economic studies, the quality assessment considered a range of factors, for example, whether all relevant costs were measured, the source of unit costs, and the time horizon of the study. The economic studies were also assessed for their applicability to the current UK context, which is especially important if studies are older or if studies originate outside of the UK. The quality of the economic studies could range from having "potentially serious limitations" to "some limitations" to as good as "no serious limitations." Studies could be assessed as being "applicable" or "partly applicable." Unit costs from older UK studies or unit costs from non-UK studies were important factors that would significantly reduce the applicability of economic findings to today's UK context. Likewise, older studies and non-UK study findings were judged significantly less applicable to today's UK context if there are significant differences in the way that the health and social care systems are delivered. In our summary of the economic studies, we assessed for both the applicability of the study and if there are any other methodological limitations (see Appendix C2 for economic evidence tables).

Plain English narrative summaries were produced for each study and were presented to the Guideline Committee for each review question.

Approach to different questions

Where no robust comparative evaluation research evidence could be identified to answer questions on effectiveness directly, and where the topic area was a priority for the Guideline Committee, the review team looked to different types of studies to answer questions on:

- what might help or get in the way of good outcomes from services. Study designs that could answer this type of question included qualitative studies of views and experiences of barriers what might help or get in the way, process evaluations, and mechanisms associated with outcomes described in comparative evaluations and secondary analysis of administrative records of service use and service audits.
- how effective services might be developed and implemented. Study designs included qualitative studies of views and experiences on development and implementation of services, barriers and facilitators to service development and implementation described in single group pilot studies, and process evaluations, secondary analysis of administrative records of service use and service audits.

We conducted narrative synthesis in the form of evidence statements as the diversity of study designs, outcomes and variable quality was not suitable for formal meta-analysis.

Economic studies were included to answer the research questions about types of services (RQ1.3), access to services (RQ4), capacity (RQ2) and models of service delivery (RQ3.2). Additional economic analysis on respite care was also undertaken (see Appendix C3).

Relationship with the clinical guideline for people with learning disabilities and behaviour that challenges

The current clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges) covered the content of assessment and management programmes but did not look at how the arrangements of different services should best work together.

Where there was overlap with the clinical guidelines, the Guideline Committee considered the evidence underpinning recommendations that were relevant to delivery of services and how services worked together as a whole. Review questions were adapted and expanded to include evidence and types of studies that would complement what was recommended in the clinical guideline.

For RQ3 that looked at models of services delivery, the clinical guideline recommended the use of a care pathway to connect people from inpatient services to community based services and reduce delayed discharges for social reasons. This review looked to different types of studies to answer a question on how a care pathway could be effectively implemented, such as process evaluations and single case studies.

RQ5 considered effective ways of integrating services. The committee notes that there is broad agreement in the clinical guideline and across other guidelines (Older people with social care needs and multiple long-term conditions [NG22]) and current UK policy (Department of Health 2017) that services are more effective for people when they are integrated. This review expanded the types of studies to answer this question by looking at what mechanisms were effective in achieving this, including not only when services work together, but working with people with learning disabilities and their families and carers, and how to help with people with learning disabilities and their families and carers to develop those services.

3.1 Types of services

Introduction to the review question

The purpose of this review, which comprises 4 questions, was to assess the effectiveness and cost-effectiveness of different types of community-based services for people with learning disabilities and behaviour that challenges (including residential) and inpatient services. We also reviewed what people said about their views and experiences of services.

We included studies that measured the effectiveness of different types of services and studies were included if they included a control or comparison group. The criteria for qualitative studies is that the study had to include textual data on the views and experiences of people who had experienced different types of community-based and in patient services.

There was little high quality evidence that could tell us which types of services are effective and cost-effective and there were gaps in some areas.

Community services: we had a lack of evidence of what were effective services and how these could be implemented. We therefore sought evidence from an expert witness (Halton Borough County Council) to talk about their 'positive behaviour support service'. The evidence is summarised in the expert testimony section under 3.1. The full testimony from the expert witnesses can be found in Appendix E.

Housing: there was a lack of high quality research in the literature on the effectiveness, costs and outcomes of different types of housing and support. The Guideline Committee considered the issue of housing for people with learning disabilities and behaviour that challenges as very important and wanted to be able to make recommendations on different types of housing and support models in the community. Further work was undertaken by the economist on the review to synthesise the evidence in this area. See the Economics section under 3.1 for further detail.

Inpatient services: we did not find any rigorous research evidence meeting our criteria to evaluate the effectiveness and cost-effectiveness of different types of inpatient services. We sought expert testimony from a consultant forensic adolescent learning disability psychiatrist to find out more about the use of inpatient services for our population. We also sought expert testimony about 2 different experiences of community services (see community services heading above) and asked these witnesses about their experiences of inpatient services. The evidence is summarised in the expert testimony section under 3.1.

Respite care: we did not find any robust evidence on effectiveness or cost-effectiveness of respite care. There was other evidence to suggest that the Guideline Committee should made a resource-intensive recommendation for respite care.

Additional economic analyses were undertaken to assess the potential cost-effectiveness of additional respite care (see section 3.1).

Review questions

1.1. What is the effectiveness of different types of community based services (including residential) for children, young people and adults with learning disabilities and behaviour that challenges?

1.2. What is the effectiveness of different types of inpatient services (in and out of area) for children, young people and adults with learning disabilities and behaviour that challenges?

1.3. What is the cost-effectiveness of different types of services for children, young people and adults with learning disabilities and behaviour that challenges?

1.4. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different types of community and inpatient services?

Summary of the review protocol

Review questions that were developed in scoping phase were discussed with the Guideline Committee and formed the basis for developing the protocols for each question. Full protocols can be found in Appendix A.

Population

People with a learning disability and behaviour that challenges.

Parents, families or carers of people with a learning disability and behaviour that challenges.

Professionals who work with people with a learning disability and behaviour that challenges.

Intervention

Community-based services, inpatient services.

Setting

All settings where care is delivered.

Person-focused outcomes

Child development outcomes; continuity of care; families and carers stress and resilience; frequency, severity and duration of behaviour that challenges; health and social care related quality of life; inclusion in community life; service user involvement in planning, delivery and monitoring of services; service user, family and carer satisfaction.

Service-focused outcomes

Availability, access and uptake of local services; equity of access; meeting complex, physical and mental health needs; geographical variation in service provision (locally, regionally and nationally); level and type of support from care workers and carers; positive behaviour support; timely discharge; out of area placements; use of inpatient.

Phenomena of interest (for views and experiences studies)

Barriers and facilitators to access to services; experiences of stress and resilience; preferences and values; involvement in the planning, delivery and monitoring of services; inclusion in community life; independence.

Study types

Systematic reviews, randomised controlled trials (RCTs), non-randomised controlled trials, cross-sectional surveys, retrospective case note reviews. Views and experiences studies.

See Appendix A for full protocols.

How the literature was searched

A search strategy for all the review questions combined was developed and the questions were translated into a framework of 5 concepts of: a) population (people with a learning disability and behaviour that challenges), b) service provision (including models of services and service capacity) or c) risk management or safeguarding or d) integrated services or e) access to services. These reflected the question areas: types of service provision, service capacity, service delivery and integration of services. The search strategy was run between December 2015 and January 2016 and update searches were conducted between February and March 2017.

How studies were selected

Results from the searches were stored in EPPI-reviewer4 a software program designed for information management of systematic reviews. The titles and abstracts of these results were screened against inclusion criteria that were developed from the scope. Two reviewers looked at the same studies' titles and abstracts independently of each other and compared their results to make sure that the inclusion criteria were understood and applied in the same way by both reviewers.

Studies that were found to meet the initial inclusion criteria were assigned to the relevant review question and the full text was retrieved for a second screening. Studies were then considered for inclusion against the review question protocol.

The review team found 141 studies relevant to this set of review questions based on the title and abstract. Six studies were not available, the rest were located and screened again on full text. After screening against the full text we retained a total of 32 studies that met the criteria in the protocol for this question. Six studies related to the effectiveness of types of community services, 5 studies related to the cost-effectiveness of types of services, and 7 studies related to people’s views and experiences of services. An additional 13 studies were included as a part of the economics work, this is described in more detail in the following section. The review did not find any well designed studies that could identify the effectiveness of different types of inpatient services. See Appendix B for full critical appraisal and findings tables.

Additional searches in EPPI were carried out on the costs and outcomes of different housing models. This comprised the additional economics work. The rationale was that we may have excluded studies because they did not focus specifically on individuals with learning disabilities and behaviour that challenges. Therefore, these searches intended to identify and include research whose study populations had learning disabilities or intellectual disabilities but may not show behaviour that challenges.

These searches were carried out within EPPI along with submissions from the Guideline Committee. Search terms were based on keywords and topics selected by the Guideline Committee members, including: congregate vs. non-congregate settings, in vs. out-of-area placements, cluster vs. dispersed housing, characteristics of the environment and setting that influence individuals' outcomes and costs, semi-independent living vs. fully-staffed group homes, supported living, and Shared Lives.

A total of 13 studies were included after screening title and abstract for the relevant keywords, of which 7 were reviews (Barron et al. 2011; Bigby and Beadle-Brown 2016; Emerson and Robertson et al 2008; Felce 2016; Kozma et al. 2009; Mansell and Beadle Brown 2004; Mansell and Beadle Brown 2009), 1 was a quasi-experimental study (Stancliffe & Keane 2000); 1 observational study (Beadle-Brown et al 2010); 2 surveys (Deveau et al 2016; McGill and Poynter 2011); 2 discussion papers, costing studies, or case studies (Curtis 2011; NAAP 2010). These 13 additional studies were assessed for their methodological quality and can be found in a separate section within Appendix C2.

Narrative summary of the evidence

Below are the narrative summaries of included studies, including economic and cost-effectiveness studies where identified.

Allen DG, Lowe K, Moore K et al. (2007) Predictors, costs and characteristics of out of area placement for people with intellectual disability and challenging behaviour

Review question(s): 1.1, 2.1 (economics narrative summary)

See also narrative summary in section 3.2.

Organisations the authors are involved with:

1. Special Projects Team, Bro Morgannwg NHS Trust, Cardiff, UK

2. University of Glamorgan, Pontypridd, UK

Type of study: Cross-sectional study

Population: Adults with intellectual disabilities and behaviour that challenges

Country: UK

Quality score: - (it has limitations)

Background and methods

Allen et al. (2007) undertook a multiple regression analysis to identify factors that lead to out-of-area placements. The study focuses on adults with intellectual disability and behaviour that challenges. The findings are based on n=1458 individuals served by 1 NHS Trust in Wales, of which n=107 were placed out-of-area.

Findings

The findings are based on a multivariate regression model. It found that the predictors leading to out-of-area placement include:

- individuals with a history of formal detention under the mental health act,
- presence of mental health problems,
- formal diagnosis of autism,
- higher adaptive behaviour,
- behaviour leading to physical injury to the participant themselves (repeated incidents and usual consequence), and
- exclusion from service settings.

The study found that individuals living in in-area placements were living in family homes (27%) and staffed homes (55%) compared to those in out-of-area placements who mostly resided in larger-scale institutional settings (52%) and staffed housing (34%).

Comparison of service use

In-area and out-of-area placements had similar access and frequency of support from social work and speech and language therapists.

Both in-area and out-of-area placements had equally low levels of access and use of advocates.

Out-of-area placements, compared to in-area placements, had slightly higher access and use of psychologists, psychiatrists (50.5% and 56.7% vs. 42.7% and 36.7%), and care managers (64.9% vs. 47.7%).

Out-of-area placements had higher percentages with a behaviour plan (63%) compared to those living in-area (30%).

It is not clear whether access to professionals were provided directly by receiving organisations or if these were provided from the public sector. The implication being that out-of-area placements place additional pressure on local services and might undermine access to local service users (p8).

Findings

This study is not designed to answer whether in-area placements are superior to out-of-area placements. However, the survey indicates that individuals in out-of-area placements had more complex needs and yet access to services was far from superior, leading to questions about whether out-of-area placements are indeed providing ‘specialist’ services. It is also concerning considering that the majority of placements were in institutional settings, which are not in line with policy aims of deinstitutionalisation.

Costs

The study reports that the total average cost per person living in out-of-area placements was £96,000/year (2002/03 prices) (including health, social services, and education). This is based on n=97 people placed out-of-area, representing 7% of the total number supported with challenging behaviour.

The authors do not provide information on the average costs of people living in in-area placements. The authors do report the average total cost of in-area placement within a specialist NHS residential continuing care services in a 5-person community bungalow to be £97,000/year, but this is not based on data from the study sample.

We should not draw conclusions about costs given the limitations of the study.

Conclusions

Caution is advised before generalising results to the rest of the UK due to the study findings being specific to 1 region of England and that results are based on older data. However, the findings do illustrate that the commissioning of out-of-area services did not line up with expectations of better access to specialist services.

Barron D, Hassiotis A, Paschos D (2011) Out-of-area provision for adults with intellectual disabilities and challenging behaviour in England: Policy perspectives and clinical reality

Review question(s): 1.3, additional economic analysis on housing

Which organisations authors were involved with:

1. Research Department of Mental Health Sciences, University College London, London, UK

2. Camden & Islington Foundation Trust, Islington Learning Disabilities Partnership, London, UK

Type of study: Literature review and survey

Population: Adults with intellectual disabilities and behaviour that challenges

Country: UK

Quality score: +

Background

Barron et al. (2011) undertook a literature review on out-of-area placements and undertook a postal survey of 54 service providers delivering services to individuals in 5 London boroughs to identify the percentage of providers meeting service standards.

Their literature review finds that individuals placed out of area were considered to have more complex needs. This may relate to having more social impairments and lower language skills (citing Beadle-Brown et al. 2005[(4)]), have higher levels of challenging behaviour, mental health problems (citing Allen et al. 2007; Hassiotis et al. 2008; Shuwa et al. 2006[(5)]), autism diagnosis, are younger (citing Allen et al. 2007; Hassiotis et al. 2008), a lack of local specialist services (citing Shuwa et al. 2006), already no contact with family (citing Beadle-Brown et al. 2005; Mansell et al. 2006a[(6)]).

Methods

The survey is based on a survey to 80 providers serving 120 service users. Surveys were returned for 45% (n=54/120) of service users. These 80 providers deliver out-of-area provision to those originating from 5 London boroughs. Providers were spread throughout the UK and most were in South East England. The survey was conducted for 2005/2006. The sample is comprised of individuals with the highest-cost care packages, defined as costing £70k and above per year (2005/06). Providers offered various services, including pure residential settings and those offering services within a health setting. The same set of data are analysed in another study to investigate the characteristics associated with these high cost placements (Hassiotis et al. 2008). This is discussed in the following sections.

The survey measures the overall percentage of services meeting service standards criteria and results are also presented across different provider types.

Findings

There were a total of n=2 independent hospitals, n=2 NHS settings, n=1 social services settings, n=29 private settings and n=17 voluntary settings. The results of the survey show that improvements are needed across services in meeting some service standards.

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[4] Beadle-Brown J, Mansell J, Whelton B, Hutchinson A, Skidmore C (2005) Too far to go? people with learning disabilities placed out-of-area. Canterbury: Tizard Centre

[5] Shuwa A, Fitzgerald B, Clemente C, Grant D (2006) Children with learning disabilities and related needs placed out of borough: parents' perspective. Psychiatric Bulletin 30: 100–2

[6] Mansell JL, Beadle-Brown J, Skidmore C, Whelton B, Hutchinson A (2006a) People with learning disabilities in out-of-area residential placements: 2 reasons for and effects of placement. Journal of Intellectual Disability Research 50: 845–56

In particular, there is a need to increase the number of senior staff with qualifications relevant to individuals with challenging behaviour, especially among those in voluntary and private settings. This was not an issue in NHS, social services or independent hospital settings.

While staff training was provided to 90%+ specific to challenging behaviour, there was an under-provision of training for mental health, a lack of ongoing training, and a lack of monitoring the quality of training. This was especially the case in voluntary and private settings and less of an issue in NHS, social services or independent hospital settings.

An improvement is needed in the management of service users, especially as there was a lack of support plans in place. This was especially an issue for private settings and less of an issue in NHS, social services or independent hospital settings.

There needs to be an improvement in providing access to a wide range of professionals as a part of a multidisciplinary team. Services provided the best access to psychiatrists, and this was consistent across provider type. There is varied and less access to psychologists, speech and language therapists, nurses and occupational therapists, and this was true across all provider types (voluntary, private, NHS, social services) with the exception of independent hospitals, which provided the most comprehensive access.

All services and provider types did well in relation to keeping records of all episodes of challenging behaviour.

A low number of services use medication as a part of managing challenging behaviour, however this varied depending on provider type – 90%+ independent hospitals, NHS, social services and private settings used medication as a part of management of challenging behaviour. This was much lower for voluntary services.

Almost 50% of services used restraint/physical interventions as a part of the management of challenging behaviour. This was used in all independent hospitals and NHS settings but much less in private, voluntary and social services settings.

Considerations and conclusions

The results of the postal survey are partly applicable. This is not a geographically representative survey. Findings are based on older data. Findings focus on a specific group of individuals with the highest cost care packages. Findings may not generalisable or applicable; caution is advised when making recommendations based on this evidence.

The quality of the survey is limited by the 45% response rate. Likewise, there is a risk of bias due to self-report, which may make results more seem more favourable than in reality.

This survey focuses on service standards. It would be beneficial to compare these to individuals' outcomes as measured by quality of life or other individual-oriented measures. Process outcomes do not necessarily tell us how individuals are affected.

The service standards in relation to staffing qualifications, staff training, use of support plans, access to various professionals and record-keeping are key components of a good quality service. Whether the levels of medication use and physical restrains for this group of individuals are appropriate is unclear as this depends on what is considered best practice.

Beadle-Brown J, Mansell J, Cambridge P et al. (2010) Adult protection of people with intellectual disabilities: incidence, nature and responses

Review question(s): 1.1, 1.3, additional economic analysis on housing

Organisation the authors are involved with: Tizard Centre, University of Kent

Type of study: prospective cohort study

Population: Adults with intellectual disabilities

Country: UK

Quality score: ++

Background

Beadle-Brown et al. (2010) compared the types of abuse and neglect experienced by adults with intellectual disabilities living in out-of-area vs. in-area placements based on referrals data from 1998 to 2005.

Data are from 2 local authorities in South East of England. Data include information about the referral and response. A total of n=1926 cases related to individuals with intellectual disabilities, of which n=1224 were those placed locally compared to n=339 who were placed out-of-area. Mean age was 38.9 years (range=17–100 years), 95% were white and 58% were female.

Methods

The study is not designed to answer questions about whether individuals are more or less likely of being abused. This study is only designed to answer whether patterns of abuse are similar or different among those individuals referred to local authority on suspicions of abuse.

Findings on patterns of abuse

Out-of-area placements had greater numbers of referrals for ‘multiple types’ of abuse (42%) compared to in-area placements (31%) (p=0.001) (p579, Table 5).

Location of abuse was also significantly different between placements (p<0.001). For those in out-of-area placements, 86.5% of abuse occurred in residential care whereas for in-area placements 49.1% of abuse occurred in residential care and 22.9% in individuals’ own homes.

There were no differences between placements with regard to the percentage of abuse occurring in public (7.2% vs. 7.2%) (p579, Table 5).

For both placements, physical abuse was the most common type of abuse, but was higher for out-of-area placements (51.2%) than for in-area placements (45.4%) (p580, Table 6).

For both placements, sexual abuse referrals were similar for out-of-area and in-area placements, respectively (20.5% vs. 21.3%).

There were higher rates of psychological abuse in out-of-area placements than for in-area placements, respectively (32.4% vs. 22.7%).

There were also higher rates of neglect and institutional abuse for out-of-area placements than for in-area placements, respectively (27.9% and 21.9% vs. 16.8% and 6.7%).

In-area placements were more likely to experience financial abuse (19.7%) compared to those in out-of-area placements (11.9%) and this reflects that most people in out-of-area placements were living in residential care.

Discriminatory abuse occurred the lowest in both placements, but was still higher in out-of-area placements than in in-area placements (6% vs. 3.7%).

In relation to perpetrator, individuals in out-of-area placements were more likely to experience abuse by more than 1 perpetrator (17%) than in-area placements (3.9%) ($p<0.001$).

Out-of-area placements had higher percentages abused by staff (including day and domiciliary staff) (55.1%) compared to in-area placements (33.4%). However, in-area placements had higher percentages experiencing abuse from family carers (27.4%) compared to those in out-of-area placements (1.7%).

Out-of-area placements had higher percentages experiencing abuse from other service users (36.8%) compared to in-area placements (24.5%) but they had lower percentages experiencing abuse from a home manager or owner (3.4%) than those in-area (10.3%). These findings reflect the differences in residence between in-area and out-of-area placements.

Findings on local authority response to referrals

With regards to follow-up, out-of-area placements had:

- a higher percentage of referrals proceed with an investigation (93.5% vs. 86%, $p=0.001$),
- a higher percentage of those investigations resulted in a confirmed case of abuse (54.2% vs. 38.9%, $p<0.001$),

- higher percentage involving a joint investigation from police, social services, and health authorities (18.4% vs. 11.1%, p=0.001),
- higher percentage involving inspection and registration (40.2% vs. 13%, p<0.001),
- fewer percentage resulting in no further action (6.2% vs. 16.4%, p=0.001),
- higher percentage increase in monitoring by the placing authority (39.5% vs. 13.5%, p<0.001) and regulatory authority (26.2% vs. 13.5%, p<0.001) but
- less monitoring by local care managers (28.1% vs. 44.9%, p<0.001), which the authors say is a result of placing authorities needing to be responsible for their own clients rather than the receiving authority (p581).

Considerations and conclusions

This study cannot tell us whether in-area or out-of-area placements have higher or lower frequencies of abuse. This is because the study information focuses on those referred. We would need to have information on the number of individuals who were not referred in addition to those referred in order to know whether people living in in-area or-out-of-area placements are at greater risk of abuse.

In conclusion, this study can only tell us that patterns of abuse are different depending on whether individuals are living in in-area or out-of-area placements.

Bigby C, Beadle-Brown J (2016) Improving quality of life outcomes in supported accommodation for people with intellectual disability

Review question(s): 1.3, additional economic analysis on housing

Which organisations authors were involved with:

1. Living with Disability Research Centre, La Trobe University, Bundoora, Vic., Australia

2. Tizard Centre, Kent University, Kent, UK

Type of study: realist literature review

Population: People with intellectual disabilities

Country: UK

Quality score: +

Background

Bigby and Beadle-Brown (2016) undertook a literature review to understand the theories and variables that influence service quality and individuals' quality of life.

Methods

The literature view included research from 1970 to 2014. The review takes a 'realist' approach whereby the scope is broader and is not limited to a finite set of papers as in a systematic review. The purpose is to 'identify the body of working theories that lie behind an intervention' (p2) in relation to supported accommodation, defined as small group homes with either 24-hour or flexible support, either living alone or sharing. A range of papers was identified, including: commentary/opinion, ethnographic studies, conversation analysis, mixed methods, qualitative interviews, quasi-experimental studies and literature reviews.

Findings

In relation to staff working and managerial practices, the strongest evidence available indicates that 'practice leadership by front-line managers in the development and maintenance of staff working practices that reflect Active Support' (p7) is likely to have a positive indirect impact on individuals' outcomes via staff working practices. While this is not based on evidence from randomised controlled trials, this is based on research spanning 40 years, totalling n=1400 individuals, using various methodologies, across different countries settings, and with various research teams and training methods (p6).

In relation to culture, the authors conclude that while this is proposed as being a very important factor influencing outcomes, this is an under-researched area.

In relation to organisational characteristics, policies and processes, there is limited research in this area. However, there is qualitative evidence that organisations that have their values translated into clear expectations of staff are likely to have a positive impact on individuals' outcomes. However, this research has mostly focused on organisational processes to increase individuals' level of engagement, and there is not much research on other organisational goals.

In relation to training, the review authors find that the strongest evidence available is the provision of hands-on training in active support.

In relation to staff characteristics, there is limited research. What research is available has mixed results.

The research on level of staff support (termed 'resources' by review authors) and size and type of settings concludes that this area has the strongest research base, mainly from the deinstitutionalisation research. They find there is strong evidence to support that outcomes are better in 'small' (up to 6), ordinary settings (i.e. that represent what would be culturally accepted and fall within the range of housing options that other people without disabilities would access), that are homelike, and are dispersed within a community (preferably their local community); (ii) outcomes are better where there are enough staff (who have the right skills) to meet people's needs but not too many that they interact with each other or do everything for people rather than enabling and empowering people to do things themselves' (p11). They also found that outcomes are better when individuals are not congregated together.

In relation to external factors, such as standards, inspections, family influence and wages, there is generally very little research in this area. However, 2 studies have highlighted that inspector ratings focus on management, staff training, systems and processes, but do not monitor other quality of life outcomes for service users.

Considerations and conclusions

This review is limited in that it is not a systematic review, and only draws on a 'purposive sample of literature that traced ideas back over time and reflected the diverse analytical approaches and opinions' (p2). It is unclear but unlikely that all relevant research is included, especially in relation to effectiveness research. Furthermore, study quality was judged on 'fitness for purpose' rather than a criterion checklist.

Brown RI, Geider S, Primrose A et al. (2011) Family life and the impact of previous and present residential and day care support for children with major cognitive and behavioural challenges

Review question(s): 1.4

Population: Children

Country: UK

Study type: Qualitative study of views and experiences

Quality score +

This study took place in Camphill School Aberdeen (CSA), a residential school in Scotland. The researchers conducted one to one interviews with 19 parents and focus groups with 7 parents of 23 children (average age 12.7) who attended full day care services. We have taken only the views and experiences parents describe in the one-to-one interviews.

Parents were asked about:

- their experiences of family life before their child went to CSA,
- their experiences of family life after their child went to CSA,
- their child's behaviour before they went to CSA,
- child's behaviour now.

We were able to group what the parents said in this study about these topics we found in the other studies.

Access to support

Families often described a lack of support for the family and a lack of respite before their child went to CSA. There was a range of different ways of using CSA services, with some children coming home for weekends, and some staying at CSA for a few nights per week.

Family life

Improvements in the children's behaviour meant that families could sometimes go out together and have more fun together as a family.

The future

Many parents said they now had a more positive outlook for the future for themselves, their family and their child. Some parents felt that this was a result of attending the school.

Impact on carers

Families often reported that before their child attending the school that caring for their child impacted on their ability to work and family relationships.

Inclusion/isolation

Before their child had started attending the school, many parents reported that they had little or no social life, and had become isolated in their communities. Sometimes this affected the social life of siblings and reduced opportunities in terms of education and employment choices. The authors describe this as social exclusion for the family as well as for the child with a disability. After their children had started attending the school many parents reported that they were now able to do ordinary everyday things, like shopping and going out.

Love and respect

There was a positive impact on siblings, and improved, more relaxed family relationships. Families said that they appreciated the time spent together more than they did before.

Stress and strain

Families felt less stress and strain at home as they were more relaxed and able to sleep etc. They also pointed out that they may not have realised just how stressed they were at the time until their child was able to go to the school.

Considerations

The study points out that parents were asked to remember a time in the past when their children lived with them full time and whether the amount of relief and optimism about the school and their child's behaviour may be due to the fact that things were stressful and at times desperate at home before their child accessed the school.

There was little information on how parents experienced other services before their child started at the school and the common theme seemed to be that there was little provision of services before the school, so we can't compare between the effectiveness of different services or say whether other services might have been preferred or equally acceptable had they been available.

The original reason for doing the study was to see what impact major roadworks were having on the children who lived there, as many of the children were extremely sensitive to noise. Different questions may have been asked of parents if the study had set out to find out about parents' views and experiences of how their past experiences compared to the present from the start.

Browning M, Gray R, Tomlins R (2016) A community forensic team for people with intellectual disabilities

Review question(s): 1.1, 2.1

Organisations authors are involved with: Community forensic team, learning disability service, Birmingham Community Healthcare NHS Trust

Type of study: Retrospective case note review

Country: England, UK

Population: People with intellectual disabilities supported by a community forensic learning disability team

Quality score: -

Type of service: Community forensic learning disability team

Aim of the study

The study aimed to find out more about the characteristics of adults with learning disabilities who were supported by a community forensic learning disability team (CFT) and the types of services delivered.

Characteristics of the service

The service was a multidisciplinary team that included input from psychiatry, nursing, psychology, speech and language therapy and occupational therapy.

A total of 30% of service users had received offence-specific interventions such as adapted sexual offender treatment programmes, fire-setter treatment programmes (FSTPs), anger management and thinking skills.

Support from the CFT is generally provided on a long-term basis, with service users being open to the team for an average of almost 2.5 years.

Characteristics of people who used the service

The majority of service users (74.3%) had a mild intellectual disability. It was common in this group to have multiple mental health and/or physical health problems and over a quarter (28%) used drugs or alcohol.

Sexual offences were the most common index offence, followed by assault and fire-setting. The majority were male (94.3%) (mean age of 37.1) and the largest proportion aged 21–30 years (32.9%).

Almost half of service users had been victims of physical or sexual abuse or neglect in their childhood (48.6%). In total, 22.9% experienced more than 1 form of abuse/neglect.

Alcohol and/or drug use played a part in the main recorded offence of 12 (17.1%) service users, that is, they were intoxicated when committing the offence.

Findings

Following referral to CFT, over half of service users had engaged in no further offending behaviours (51.4%). Assault was the most common re-offence, followed by sexual offences, destruction/vandalism and threatening/offensive behaviour. Those engaging in fire-setting behaviours reduced after referral from 14.3 to 1.4%.

There was a decrease in the number of people committing contact sexual offences and sexual offences against under 16s.

Fewer individuals received any criminal convictions because of their behaviour (54.3% at index offence vs. 7.2% after referral).

There was a slight increase in people committing offences, where police were involved, but no charge was brought, from 17.1 to 24.3%.

Over 2-thirds of all service users had received input from speech and language, occupational therapy and psychology.

There was also a change in where people lived once they had been referred to and were receiving care from the community forensic team. At time of referral to the CFT, 44.3% of people were living in secure units; 44.3% were living in the community; 7.1% were living in trust forensic step-down units and no service users were in prison. At the time of the service evaluation, 27.1% of people were living in secure units; 54.3% were living in the community; 12.9% were living in trust forensic step-down units and 5.7% were in open ward hospitals. There was a reduction in people in secure units (which are out of area) from 44.3 to 27.1% and an increase of people living in the community from 44.3 to 54.3%.

Considerations

The retrospective case notes review relies on the accuracy and detail that was recorded at the time. It is limited to telling us only about people who were referred to the service, but not about people who were not, or who were not known to services.

The study does not compare to another comparable group, or a national baseline figure to reveal whether the numbers of people who committed another offence was lower than usual and it was not clear how severity was measured or if it was appropriate to think of a reduction in severity as an outcome.

The follow-up times available in the case notes was only up to 2 years, so it may be that rates of reoffending go up over time, or reduce as people get older.

However, the reduction in people in secure units who were now being supervised and looked after by the community forensic team is likely to be representative of that community. This shows that the service was able to shift care for people with forensic needs who might have been referred to an inpatient secure unit into the community.

The increase in the proportions of re-offences where the police were involved but no charges brought may indicate the forensic team had better links with local criminal justice agencies and there was a greater willingness to divert away from CJS into forensic care into the community where there was service involvement associated with the individual.

The proportion of people using this service who had experienced abuse themselves is also found in offenders who don’t have learning disabilities. People with a dual diagnosis of problems with drugs and/or alcohol was also relatively common, but links to drug and alcohol services were not indicated in this service.

Curtis L (2011) PSSRU Unit Costs report. “Shared Lives – model for care and support

Review question(s): 1.3, additional economic analysis on housing

Organisations the authors are involved with:

1. Personal Social Services Research Unit

2. Shared Lives Plus (formerly NAAPS UK)

Type of study: Costing study

Population: People with intellectual disabilities

Country: UK

Quality score: −

Background

The PSSRU Unit Costs (2011) provides information about the potential savings if individuals with learning disabilities are offered Shared Lives (Curtis 2011: 12). Shared Lives is a Care Quality Commission (CQC) regulated scheme whereby an individual needing social care support lives with another family who are trained and carefully selected.

The Shared Lives scheme is distinct from other types of housing models in that Shared Lives carers can support a maximum of 3 individuals. Carers cannot employ staff to get additional support but can request additional support from the Shared Lives scheme. The scheme is of mutual benefit to the carer and the individual. The Shared Lives carer provides their family home as a resource, and is a part of the carer's social network and community, and matches are made through a careful process (Curtis 2011: 12).

Methods

The information on Shared Lives is based on a report from the NAAPS (2010) and the Information Centre (2010). The Information Centre (2010) provides statistics on the number of people using Shared Lives schemes. The NAAPS (2010) estimates the costs of Shared Lives.

Findings

As of 2009, a majority (88%) of Shared Lives schemes were used by individuals with learning disabilities, although they are also used by adults with other types of needs (Curtis 2011: 12).

The NAAPS (2010) found that the CQC gave 79% of Shared Lives schemes a rating of 'good or excellent' compared to 69% of learning disabilities care homes (Curtis 2011: 12).

The estimated long-term average cost of Shared Lives scheme for an individual with learning disability and who would otherwise live in residential care is £419 per week (in 2009). This includes care and support, board and lodging, and management costs (Curtis 2011: 13-4). Approximately 70% of this cost is comprised of care and support provided by the Shared Lives carer (£293/week) (Curtis 2011: 14). For an individual with lower levels of need and who would otherwise live in semi-independent living arrangements, the estimated long-run average cost is £293/week (2009 prices), which includes a flat management fee of £58/week (Curtis 2011: 14).

Considerations and conclusions

The findings on the costs of Shared Lives must be treated with caution given the lack of information on costing methods. Robust research is needed to understand the impact of Shared Lives on individuals' outcomes and the cost of providing Shared Lives schemes.

Davis A, Doyle M, Quayle E, O'Rourke S. (2015) 'Am I there yet?' The views of people with learning disability on forensic community rehabilitation

Review question(s): 1.4
Organisations authors are involved with:

1. Willow Service, NHS Lothian, Edinburgh, UK
2. Department of Psychology, Lynebank Hospital, Dunfermline, UK
3. Department of Clinical Psychology, University of Edinburgh, Edinburgh, UK.

Type of study: Qualitative, interviews of people's views

Country: Scotland, UK

Population: Adults with community forensic needs in 2 health board areas of Scotland (Tayside and Fife). All participants had a learning disability and a forensic history and were subject to a legal order requiring them to accept high levels of supervision due to the risk they presented to the public.

Quality score: ++

Type of service: Community forensic services

Aim of the study

To find out what people with a learning disability subject to a forensic community rehabilitation order think about the services they receive.

Characteristics

Ten male participants took part in the study. No females were involved because there weren't any using the services.

Age range in years: 23–49. All participants has a significant learning disability. Most (n=8) had an index offence of sexual offending or sexually inappropriate behaviour.

Time on order: 1–15 years
Type of order: Compulsory treatment order (n=6); guardianship order (n=3); compulsion order (n=1)

Previous living arrangements: Secure hospital (n=8); hospital house (n=1); living with family in the community (n=1)

Findings

Most people felt they did achieve some positive benefits from living in a less restricted environment.

Five main themes emerged from the data.

Freedom within limits

Most people felt there was an opportunity within their community order to try new things: for example, joining classes and groups, and enjoying holidays.

'Well, it's easier from my, it's easier for me, eh? It just […] makes it a lot easier for me as well to, to go out and do things that I've never dreamt of doing' (participant 7) (p154).

Participants also expressed a sense of autonomy and choice in their daily lives, which they viewed very positively. One participant talked about a weekly planner and deciding themselves what went into it. However, frustration was also expressed by some that the freedom was not all it could be and there were still limits:
'Eh, I felt like […] I says to myself, this is rotten – I can't do what I used to do when I was in the [hospital]' (participant 3) (p156).

Some participants ‘reminisced about their time in hospital, with close living quarters and shared social events creating a sense of community, which appeared lacking in the actual community setting.

Loss of control

Participants talked about not ‘having control over their situation’. They didn’t know what the ‘rules are’ and felt that staff had too much control. Most participants thought the main role of staff was giving support with household tasks:

‘[…] I’m cleaning the hoose. Why don’t they just come in and help? No.’ (pilot participant) (p155)

There was also a consistent feeling throughout participant response that they had not ever had the chance to consider and reflect on some aspects of their care. Participants also described a lack of control in relation to their care plan, feeling that their progress was dependent solely on the subjective judgement of others.

Attempting to get control back

Participants attempted to regain control though advocacy groups or via their lawyers; by more passive–aggressive behaviours such as ‘sneaking’ extras, refusing to engage, or employing a ‘keep your head down’ approach; or by giving up and ceasing to try:

‘[…] I’m keep on nowadays progressing with my independent living. I’m not giving any of these professional people any excuses or any cases to argue’ (participant 9) (p157).

Loneliness

Participants described very limited social networks and difficult family relationships and maintaining the relationships they did have, due to staff presence:

‘Aye – ha’ing staff. I got to lie. But the second time you go and meet them with someb’dy else, “who’s that?”. “Oh aye, that’s my brother.” You cannae, you cannae win that way eh?’ (participant) (p157)

Also, for many participants, staff became like friends due to shared activities, contact over time and lack of others in their lives. It was difficult for them to consider moving on and not having staff with them all the time.

‘I don’t know if it’s be […] I’ll be really honest, I think I’d be lost.’ (participant) (p157)

However, not everyone reported loneliness; and some reported feeling that family relationships were actually eased by the presence of a third party.

Stigma of a service user

Participants appeared to experience more shame associated with needing help to care for themselves and having someone with them at all times in public, than with being seen as a risk to the public:

‘And I don’t want to learn to read and write, If I do, I’m learning on the computer myself, I’m no wantin’ someone to come along and do it for me.’ (participant)(p158)

The quote below captures the frustration most participants seemed to feel regarding the compulsory care they received.

‘It’s just […] sometimes I feel like eh […] I could do without them, and other days I’m no wantin’ them, and other days I do want them. And some days I feel like I’ve just done enough time, being in prison and all this crap ya ken? I’ve just done enough time, being in here and […] I just feel like I’ve done enough’ (pilot participant) (p158).

Considerations

The authors say that this is the first piece of research that looks at compulsory forensic care for people with learning disabilities from the perspective of people that use services. Ethical issues were particularly important in this study and the researchers took care to address them. For example, maintaining confidentiality in such a small and closely supervised population and building a relationship with the participants before the interview took place in order to encourage participants to express their true views.

Participants did have difficulties with expression, comprehension, and speech which reflects the general difficulties with communication for this group. Participants’ learning disabilities may also affect their understanding of the support services they are being offered although this should not detract from the feelings described in the study.

This was a very small study and most of the participants had an index offence of sexual offending or sexually inappropriate behaviour, so you need to consider if their views would be representative of people subject to compulsory care or high level of support that display other forms of challenging behaviours.

Improving the model

The views of people in this study suggest that there are 4 areas that need to be addressed to improve care in this model.

Better understanding of the system: part of the disempowerment participants expressed in this study was due to not understanding the roles of the support team around them and what to do in order to have their legal order removed, which suggests that more discussion needs to take place with people that use services so they get a better understanding of the system.

Role clarification: it would be helpful for people that use services and staff teams to have a better understanding of their dual roles of support and public safety.

Clear care pathways: care pathways need to be shared with people who use services and services need to be transparent in explaining to people who use services that they will be helped to have as meaningful a life as possible within the restrictions of their community order.

Tackling internalised stigma: if the team around the individual is more open about the individual’s difficulties, this may encourage the individual to do similarly.

Empowering support staff: encouraging teams to reach a shared understanding of the individual, in terms of psychological factors which may drive his/her behaviour and resulting needs.

Deveau R, McGill P, Poynter J (2016) Characteristics of the most expensive residential placements for adults with learning disabilities in South East England: a follow-up survey

Review question(s): 1.3, 2.1, additional economic analysis on housing

Organisations the authors are involved with:

1. Tizard Centre, University of Kent

2. Surrey County Council, Kingston upon Thames, UK

Type of study: Cross-sectional survey

Population: Adults with intellectual disabilities

Country: UK

Quality score: +

Background and methods

Deveau et al. (2016) undertook a follow-up survey to the research carried out by McGill and Poynter (2011) of the highest-cost placements for individuals with intellectual disabilities from 14 local authority areas in the South East region of England (below). The sample size increased to n=105 since the last survey (n=70).

Findings

They found that the cost of in-area and out-of-area placements were not different, which was the same finding in the earlier 2009/10 survey.

The mean cost of an out-of-area placement was £202,000 compared to an in-area placement of £198,000 (2011 prices). The mean placement cost for all placements was £200,000, with a range between £81,00 and £430,000. A majority of placements were provided by the private sector (82%), not-for-profit (10%), the NHS (4%) and local authorities (4%).

However, the findings of the surveys were different in relation to the percentage of high-cost individuals in out-of-area placements and the predictors of out-of-area placements.

Compared to 2009/10, there were fewer high-cost placements in out-of-area (57% compared to 71%).

In the 2009/10 survey, the only predictors of out-of-area placements were:

male gender,

living in residential care,

not living in supported living arrangements.

In this follow-up survey, those characteristics were no longer predictors. Instead, statistically significant predictors of out-of-area placements include:

a mental health diagnosis,

offending behaviour,

being in hospital, and

being in a secure or medium secure unit.

Statistically significant predictors of in-area placements include:

having autism,

a physical, sensory, or health impairment,

having supported living arrangements, and

being funded by local authority.

There were also changes in the predictors of higher-cost placements compared to the previous 2009/10 survey. In the 2009//10 survey, higher cost placements were predicted by:

- age,

- level of intellectual disability,
- challenging behaviour, and
- having a genetic syndrome.
- In this follow-up survey, predictors of higher-cost placements were:
- female gender,
- offending behaviour,
- attending residential school, and
- those funded by continuing health care.

Furthermore, lower costs were predicted by funding from local authority.

Overlaps in the predictors of both higher cost placements and being placed out-of-area were offending behaviour, which may lead to placement in a secure or medium secure unit.

Considerations and conclusions

It is important to remember that this survey focuses on a very narrow sample of individuals. The survey asks local authorities to report on their highest-cost placements.

Emerson E, Robertson J, Robertson J, Dorr H, Russel P, Spencer K, Davies I, Felce D, Allen D, Churchill J, Rose S, Maguire S, Hatton C, Madden P, Mills R, McIntosh B, Congdon D (2008) Commissioning person-centred, cost-effective, local support for people with learning difficulties

Review question(s): 1.1, 1.3, additional economic analysis on housing

Organisations the authors are involved with:

1. Institute for Health Research, Lancaster University

2. Central England People First

3. Welsh Centre for Learning Disabilities, Cardiff University

4. Unit for Development in Intellectual Disabilities, University of Glamorgan • National Family Carer Network

5. ARC (Association for Real Change)

6. Mencap

7. National Children's Bureau

8. National Autistic Society

9. Foundation for People with Learning Disability

10. HFT (The Home Farm Trust Ltd)

11. Choice Support.

Type of study: Literature review

Population: Individuals living in out-of-area placements

Country: UK

Quality score: −

Background and methods

Emerson and Robertson (2008) undertook a literature review on out-of-area placements based on both grey literature and peer-reviewed journal articles. This includes research based on total population surveys of several geographic areas, including the studies that we have reviewed: Hassiotis et al. (2008), Allen et al. (2007) and Joyce et al. (2001). The authors report that the evidence base in this area is relatively small (p8) and study samples vary.

The review includes studies looking at individuals with disability in out-of-area placements, individuals with challenging behaviour (Allen et al. 2007), individuals with learning disabilities in high-cost placements (including Hassiotis et al. 2008), individuals with complex mental health needs and those with severe learning difficulties, young people with learning disabilities in transition to adult services and those with forensic and secure needs (p13).

Findings

Based on these studies the authors conclude that individuals with intellectual disabilities and who have challenging behaviour, autism, mental health needs, complex health needs and forensic needs were more likely to be placed out-of-area (p20).

The authors find some evidence that people placed out-of-area may be more able and show behaviour that is more challenging or has more severe impact (p21). Reasons for out-of-area placements were mainly due to a lack of available local services, placement breakdown and dissatisfaction with local services. Positive reasons for out-of-area placements were less frequent but did include being nearer to family or individual preferences (p21).

The authors also find that most out-of-area placements are operated by the independent sector and a majority of placements are in large settings (p21). Given the high expectation that out-of-area placements are more specialised, survey data indicate many shortcomings in relation to: access to appropriate health and social care professional support; low use of person-centred centred plans; low engagement levels in home and community activities; and a lack of appropriate support for those with complex needs (p22).

The costs of out-of-area placements were slightly more costly than compared to in-area placements. Findings from some studies revealed that local services rather than agencies' specialist provision were provided to individuals in out-of-area placements (p22). This finding is concerning considering that money could be invested into in-area placements.

The authors propose some recommendations aimed at the Departments of Health and Education, national advocacy agencies, commissioners and providing agencies.

Considerations and conclusions

The findings of this review must be treated with caution. This is because the review has limitations. These limitations include the lack of reporting methods for the literature search (inclusion/exclusion criteria, databases), meaning we do not know whether all relevant research is included. Likewise, the review does not report on included studies' quality or whether study quality was assessed, meaning it is unclear whether reported results are reliable.

Felce D (2016) Community living for adults with intellectual disabilities: unravelling the cost-effectiveness discourse

Review question(s): 1.1, 1.3, additional economic analysis on housing

Organisation the author is involved with: Cardiff University

Type of study: Systematic review

Population: Adults with intellectual disabilities

Country: UK

Quality score: −

Background

Felce et al. (2016) reviews the evidence on the costs and effects of residential services for adults with intellectual disabilities.

Methods

The review does not report methods for data extraction or assessment of study quality and does not provide a detailed report of sample characteristics. Without going back to each individual study, this makes it difficult to assess the reliability of the findings and the generalisability to UK policy.

1. Findings on the impact of deinstitutionalisation on outcomes

The review first focuses on the impact of deinstitutionalisation literature on outcomes and suggests that some conclusions can be drawn about its impact, and the influence of service characteristics on individuals' outcomes.

Of particular relevance to this report is a review of 71 UK and Irish studies between 1980–99 (Emerson and Hatton 1996). That review found that individuals who moved from institutional care to staffed housing in the community did not have improvements in social networks, but a majority of studies did find improvements in competence and personal growth, community participation, engagement in meaningful activity and contact from staff.

A more recent review of 67 studies from the UK, America and Australia (Kozma et al. 2009) conducted between 1997 and 2007 found that a majority of studies also found improvements in community participation and self-determination and choice and, in contrast to the older UK review, these studies did find improvements in social networks and friendships. This more recent review also found improvement in quality of life, adaptive behaviour, user and family views and satisfaction and family contact. This also finds support from an older review of 13 Australian studies (Young et al. 1998) conducted between 1985 and 1995 that also found improvements in client satisfaction, community participation, contact with family/friends, interactions with staff and parent satisfaction. In contrast to the more recent review, a majority of studies found no differences in adaptive behaviour. This review also found a majority of studies finding no differences in community acceptance and health/mortality. Impact on challenging behaviour is not entirely clear.

An older review of 13 Australian studies conducted between 1985 and 1995 found mixed impact on problem behaviour (Young et al. 1998) and this received support from an older review of 29 American studies conducted between 1980 and 1999, which found mixed effects, although most studies found no differences (Kim et al. 2001).

A more recent review of 67 studies from the UK, America, and Australia (Kozma et al. 2009) conducted between 1997 and 2007 also found mixed results for challenging behaviour. The review authors conclude that, on the whole, there are more advantages for living in community than in institutional settings.

2. Findings on the impact of deinstitutionalisation on costs

Regarding the impact of deinstitutionalisation on costs, the review authors state that findings are not clear due to limitations in the comprehensiveness of cost and outcome evaluation and the lack of appropriate methods.

A review of older UK studies (Felce and Emerson 2005) found that 25-person and 6- to 8-person residential settings in the community were only slightly more costly than institutional settings, although studies were limited in the comprehensiveness of the cost evaluation (3 studies). Studies conducted in the 90s were more comprehensive and found higher costs associated with community settings (4 studies).

A more informative study is a single longitudinal one which found that the cost of community-based housing was more costly than institutional settings in the first, fifth and twelfth years, but cost differences progressively declined to £29/week compared to £162/week in the first year (citing Hallam et al. 2006).[7] This study also found improvements in individuals' quality of life. In conclusion, the authors state that more research is needed to understand the drivers of costs and effects of different housing models the UK.

3. Findings on economies of scale

In reviewing the UK literature regarding setting size and economies of scale, 1 study found that average total costs per person were similar for individuals living in houses with 6 to 8 residents compared to individuals living in institutional settings with several hundred residents (citing Felce 1986). In another study of adults with very severe challenging behaviour, size was not a predictor of accommodation costs when using a dummy variable indicating institution or community setting (citing Felce et al. 2000). However, 1 study on n=109 individuals living in various community settings (residential homes, hostels, staffed group homes, independent living, foster placement and living with minimal support) found that smaller settings were more expensive but the impact on cost was small (but significant) (citing Knapp et al. 1992). This study found that setting size was 1 of 5 factors that predicted only 23% of variation in total costs (p5, citing Knapp et al. 1992). Another study of n=150 community settings with placements varying from 2 to 31 found economies of scale up to a residence size of 6, but beyond that there were no additional economies of scale (citing Raynes et al. 1994).

Another study compared individuals in supported living schemes (1–3 placements), individuals in small group homes (1–3 placements) and those in larger group homes (4–6 placements) and found no differences in absolute and adjusted costs (p5, citing

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[7] Reported costs were $271/week and $48/week at 2014 price conversion from USD to GBP (rate of $0.6 to £1).

Emerson et al. 2001). When this same study pooled the data across all settings, results were different. In particular, among individuals with greater levels of disability (ABS Part 1 score <140), there was an inverse relationship between setting size and costs, with smaller settings being associated with higher costs; however, this relationship was not true for individuals with less severe disability and there was no relationship between costs and setting size (ABS Part 1 score >140) (p6).

However, another study found that costs were higher for smaller settings when staffing levels were fixed rather than variable to meet individual need. This was based on a comparison of group homes with fixed staffing to semi-independent living with individualised staffing support (p6, citing Stancliffe 2005).

Yet another study of staffed housing with 6 and fewer residents found that housing with smaller numbers of residents cost more than housing with greater numbers of residents, even after adjusting for residents' characteristics; however, the impact on costs accounted for only 16% of the variation in residents' staffing costs (citing Felce et al. 2003).

4. Findings on factors associated with quality of life

This review also summarised the findings regarding the factors associated with quality of life in different community housing settings. They found 1 review by Felce and Perry (2007) which included matched comparative studies or studies with multivariate analyses. That review found that setting size had inconsistent evidence on impact on outcomes however, it did have an indirect impact through home-likeness and physical integration, as these factors led to better outcomes, and in this way keeping the size of accommodation typical and of standard architectural design was important. There was little research on the impact of neighbourhood characteristics on outcomes. Cost and staffing levels had mixed effects, which the review authors conclude indicates the need to match individuals' needs. This might be explained by the finding from several studies measuring the working methods of staff. Some studies found that staff spend about 33% of their time directly supporting individuals or that individuals receive staff support for about 15–20% of the time and, during this time, very little instrumental support is provided (i.e. assistance or encouragement), and that staff tended not to adjust instrumental support according to the individual’s level of ability. The authors conclude that the support provided by staff may be inefficient and therefore explain weak or inconsistent relationships between staffing levels and outcome. They emphasise the need to train staff in effective working methods, and refer to ‘active support’ as an example that is supported in the research literature.

Conclusions

In conclusion, the review authors say that the evidence is suggestive rather than conclusive in relation to the cost-effectiveness of residential services. On the other hand, they find that the evidence is conclusive in relation to the improved quality of life in community-based housing compared to institutional models. The comparative costs of institutional and community settings are not entirely clear and depend on a range of factors.

The review authors conclude that more research is needed, in particular:

- using representative study samples,
- using comprehensive methodologies for outcomes and costs,
- more research into supported living models that emphasize individual choice,
- clearly describing the settings in which people are living and more generally,
- the research community should agree on housing-related variables and characteristics that need to be reported and described so that policy implications are made more clear and everyone is in agreement as to what is being talked about.

Considerations

This review is limited by inadequate reporting on the methods used to include studies, meaning we cannot know whether a rigorous search was undertaken. Likewise, we do not know the quality of included studies and we do not know whether data extraction was carried out for each study. Furthermore, the quality of the included studies were not reported. These limitations mean we cannot check the reliability of the authors’ conclusions or understand to which specific groups of individuals the results apply (i.e. individuals with challenging behaviour) because there was not enough detail provided about sample characteristics.

Felce D, Perry J, Romeo R et al. (2008) Outcomes and costs of community living: semi-independent living and fully staffed group homes

Semi-independent vs. fully-staffed settings

Review question(s): 1.1, 1.3

Organisations the authors are involved with:

1. Cardiff University, School of Medicine

2. Institute of Psychiatry, Centre for the Economics of Mental Health

3. Lancaster University

Type of study: Economic evaluation

Country: UK

Population: adults with learning disability and behaviour that challenges

Quality score: +

Background

The aim of this UK study (Felce 2008) is to assess the cost-effectiveness of semi-independent vs. fully-staffed residential settings for adults with learning disability and challenging behaviour with low to moderate support needs. Residences were described as group homes for four people or fewer.

In the study, semi-independent living was defined as “having no paid staff support for at least 28 hours per week when service users were awake at home. These settings also had no regular night-time support or sleepover presence” (p.89).

Fully staffed group homes were defined as “staff presence during waking hours at all times that service users were present (included settings where staff members were not present during the periods of the day in which all service users were out either working or pursuing some other occupation)” (p.89).

Methods

Study participants were taken from 14 agencies that provided supported accommodation in South Wales, South West England, and North West England.

This is a non-representative cross-sectional study using a matched-comparison design. Analyses took two approaches, in the first; results were adjusted for individuals' total scores using the full versions of the Adaptive Behaviour Scale (ABS) and the Aberrant Behaviour Checklist (ABC). In the second approach, a reduced sample comparison was undertaken (n=28 vs n=27). We report significant differences in outcomes only where the two approaches had the same result.

Findings

Similarity of settings at baseline

Compared to fully staffed group homes, participants in semi-independent living were:

- younger (40 years old vs. 50 years old),
- had a more equal distribution of males to females (49% male vs. 63% male),
- had not been living in their current tenancy as long (59 months vs. 74 months),
- had higher levels of adaptive behaviour (Adaptive Behaviour Scale, 264 (sd=33) vs. 234 (sd=20)), and
- lower levels of challenging behaviour (Aberrant Behaviour Checklist, 6 (sd=7) vs. 18 (sd=19)).

Outcomes that were measured

Outcomes that were measured in the study include: staff working practices and quality of life (as measured by money management, home-likeness, BMI, exercise, health checks, healthcare and lifestyle scores, safety and risks, community involvement, social networks, loneliness, choice, participation in domestic tasks, and lifestyle satisfaction). Outcomes are measured at one point in time.

Costs

The perspective of the analysis is that of the NHS and personal social services. Costs included accommodation and non-accommodation costs.[8]

Accommodation costs were collected from agency accounts and included direct staffing in the setting, non-staffing costs (utilities, food), on-site administration, and central agency overheads.

Non-accommodation costs were measured using the Client Services Receipt Index (CSRI), which records the use of welfare benefits, income, and health and social care services in the previous 3 months. Costs reflect the 2003/2004-price year.
Results

The study found that semi-staffed homes were less costly and have advantages on some outcome measures; on the other hand, fully staffed group homes were more costly but offer advantages on other outcome measures (£379 (sd=243) vs. £1076 (sd=447)).

The study found that, semi-staffed homes were less costly and have advantages on some outcome measures; on the other hand, fully staffed group homes were more costly but offer advantages on other outcome measures (£379 (sd=243) vs. £1076 (sd=447)).

The authors looked at lots of different measures for quality of life and service quality, but only found a few big differences, these were:

- people who lived in semi-independent homes,
- people who were more likely to have money problems,
- people who were less likely to have a garden,
- people who were less likely to have had their eyes tested in the past 2 years,
- people who had poorer health related to their lifestyles, and
- people who had less variety in their community activities.

On the other hand, people who lived in the semi-independent homes were:

- more likely to have taken part in community activities on their own,

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[8] Authors report costs in American Dollars but we have re-calculated costs into Pounds Sterling using the exchange rate they have provided in the paper (£1 = $1.4306 = $1 = £0.699).

- more likely to have a social life beyond their family and the other people who lived in the semi-independent living home, or staff,
- more likely to have done domestic and household jobs,
- more likely to say that they had choice and control in their life.

Costs

Semi-independent living had lower costs because they had lower accommodation costs This was a result of:

lower direct staffing costs (£176, sd=175 vs. £675, sd=394, p<0.0001), lower non-staff inputs (£31, sd=36 vs. £75, sd=35, p<0.0001) and lower agency overheads (£51, sd=51 vs. £121, sd=73, p<0.001),

Semi-independent living and fully-staffed group homes had similar on-site administration costs.

Semi-independent living costs were also lower because they had lower non-accommodation costs. This was due to:

less use of daytime activity services (£102, sd=90 vs. £185, sd=130, p<0.05).

Both settings did not differ in their use of hospital services or community-based professional inputs).

There are weaknesses in the economic methods, which make it difficult to be confident in the findings on accommodation costs. In particular, accommodation costs were based on local prices, without a description of accompanying level of resource inputs. This means it is unclear whether lower accommodation costs in semi-independent living were a result of lower prices or a result of less resource inputs. We can be confident in the methods of calculating non-accommodation costs, as differences in costs are based on differences in actual resource inputs, and not based on differences in local prices. A further limitation of this economic evaluation is the short time horizon of the analysis, which spans only 3 months.

Considerations

This study is of low to moderate quality. This is because the study does not use a randomised design. This is important because a good study design helps us be sure that the outcomes and costs are a result of differences in the services provided, and not due to other factors, like individual characteristics.

The authors tried to make the study design as good as possible, even though it was not randomised. They did this by trying to match the groups as much as possible on levels of challenging behaviour. However, the samples were different in other ways (as mentioned earlier).

However, the individuals were not exactly the same. This means that differences in outcomes and costs are not entirely due to differences in the services they received. It may have been influenced by other factors. We don’t know how much results would change if this had been a randomised design study.

This study was also based on a small number of people (70 people). It may be that the numbers of people in the study was too small to find important differences.

On the other hand, not finding big differences between the 2 groups could be a good thing if people who are living more independently are more at risk because they have more control over their life and what they do and where they go, but on the whole they were no more likely to have accidents in the home, to say that they did not feel safe, to say that they had been a been a victim of crime or that they felt lonely.

The authors suggest that semi-independent homes can be good for people with learning disabilities and behaviour that challenges, if staff give extra support to people to help them with their financial, physical health and wellbeing needs. This doesn’t necessarily mean having to have more staff, but rather providing targeted support. Sometimes having staff being around all the time can get in the way of people who want to be independent.

Based on the limitations of the study and weaknesses in economic methods, it is not possible to determine whether in-area or out-of-area placements are relatively more cost-effective.

Golding L, Emerson E, Thornton A (2005) An evaluation of specialized community-based residential supports for people with challenging behaviour

Review question(s): RQ 1.1

Organisations the authors are involved with: Psychology Services, Bolton, Salford & Trafford Mental Health NHS Trust, Prestwich, Manchester, UK

Type of study: Comparative evaluation – compares the effects of moving from 1 type of service to another with a comparison group already receiving the second service

Country: UK

Population: Adults aged 30–60

Score +

Background

This study looks at the effects of moving from institutional to specialised community-based residential support for people with severe learning disabilities and behaviour that challenges.

The people living in the institutional (hospital) group had staff available between 0700 and 2200 and there were 3 staff for every 11 residents. For people living in the community group there were 4 staff for every 6 residents and they were available between 0700 and 2200.

There were similar numbers of people living in each type of home and they were all men from the same local area.

The authors made sure that the 2 groups were as similar as possible on characteristics like behaviour. The community group was younger than the hospital group and had spent less time in institutions. However, the authors say that there is little evidence to suggest that the outcomes of deinstitutionalisation are related to either age or length of institutionalisation.

Findings

The authors looked at lots of different measures of people's behaviour and quality of life but only found a few big differences, these were as follows.

People who moved to a community-based home had:

- an increase in domestic skills,
- a decrease in the observed occurrence of problem behaviour,
- improvements in quality of life,
- higher levels of engagement in leisure activities and other tasks,
- higher levels of contact from staff.

On the other hand, people who already lived in the community also showed a number of positive changes.

For people in the group that moved into the community setting, the positive improvements were maintained 9 months after moving, except for problem behaviour where there was no change.

Considerations

It may be that the numbers of people in the study was too small to find important differences.

It is also worth noting that the use of behavioural observation methods in this study raises a few issues. First, the way the observer reacts to the person being observed might account for some of the positive changes in engagement and staff contact in the community group. Second, very little problem behaviour is actually observed during the 8 hours periods of observation. Third, the authors suggest that there might be a difference because different people are doing the observing between hospital and community settings. This suggests it is difficult to tell how much difference there was in problem behaviour during the study.

The authors suggest that moving into specialised community-based residential services specifically designed for people with severe behaviour that challenges may be good for people, which contrasts with current UK policy which suggests that such services may lead to a rise in behaviour that challenges.

Harflett N, Pitts J, Greig R et al. (2017) Housing choices: discussion paper

Review question(s): 1.3 (economic narrative summary)

Organisations the authors are involved with: National Development Team for Inclusion

Study design: discussion paper / systematic review

Country: UK

Population: People with learning disabilities

Quality score: −

Background and methods

The authors find that there is very little research on the costs of different housing and support options. There is even fewer research on cost-effectiveness. The authors find that the quality of research is limited. Most studies are costings of single cases rather than robust cost-effectiveness comparisons. They also report that there is very limited information on the unit costs of housing and support options and there is variation in the methods of calculating unit costs.

Another challenge the authors find is that terminology for different housing options is not standardised, which it makes it difficult to understand and compare results of studies on different housing and support models. The authors conclude that the evidence on costs and cost-effectiveness is unclear for different housing and support models based on current available research.

Considerations and conclusions

The conclusions of the review are consistent with the findings. However, this review has significant limitations. We cannot confirm the reliability of the findings given that the authors do not report detailed information on their search strategy and they do not report which studies they have included in their review. They also do not report included studies' quality nor report whether they undertook an assessment of quality. Altogether, we must treat the findings of this review with caution.

Hassiotis A, Parkes C, Jones L et al. (2008) Individual characteristics and service expenditure on challenging behaviour for adults with intellectual disabilities

Review question(s): 1.1, 1.3, 2.1, additional economic analysis on housing

Organisations the authors are involved with:

1. Department of Mental Health Sciences, Royal Free & University College Medical School

2. Camden Intellectual Disabilities Service

3. Department of Mental Health Sciences

4. Enfield PCT Intellectual Disabilities Service, Chase Farm Hospital, Enfield

5. Centre for the Economics of Mental Health, Institute of Psychiatry, London, UK

Type of study: Survey

Population: Adults with intellectual disabilities and behaviour that challenges

Country: UK

Quality score: +

Background and methods

Hassiotis et al. (2008) undertook a regression analysis to determine which demographic and clinical factors influence high-cost care packages and which factors influence whether individuals are placed in-area vs. out-of-area.

This study is based on a population-based survey of 5 London boroughs and focuses on a specific subgroup of individuals with intellectual disabilities and challenging behaviour with the highest-cost care packages (£70k+ per year).

They identified n=205 individuals, of which n=153 were rated as having moderate-to-severe challenging behaviour. The authors also compare service standards of in- vs.

out-of-area placements, defined by the scores awarded by the Commission for Social Care Inspection (CSCI).

1. Findings on the costs and predictors of out-of-area placements

The study finds that individuals placed out-of-area had higher mean care package costs compared to those placed in-area. Total mean (median) in-area costs across the 5 boroughs were £97,893 (£88,959) compared to out-of-area placements, £105,952 (£90,345).

Predictors of being placed out-of-area were managers' assessments that individuals' have greater needs, which is consistent with the correlations showing that these individuals have higher levels of challenging behaviour.

Having mental health problems or autism were not statistically associated with being placed out-of-area but a majority of individuals with those conditions were placed out-of-area. However, these same characteristics were statistically associated with higher cost placements and support packages.

Other predictors of being in out-of-area placements are younger age and living in certain boroughs.

2. Findings on service standards

In terms of service standards, scores were available for n=105/205 placements. Out-of-area placements had significantly higher scores than in-area placements. The authors do not present the scores so as to understand the magnitude of the difference. The authors note that lower scores tended to cluster around lower-cost placements (£70–£100k/year) but this correlation was not statistically significant. The authors report that it is not clear whether higher scores in out-of-area placements are due to more robust monitoring or whether it is due to underfunding of local providers for in-area placements.

The authors report that a limitation of the study is that costs are not disaggregated, meaning that it is not clear where the balance of care lies across sectors or services and whether the balance of care is different between in- and out-of-area placements and clinical and demographic characteristics.

Considerations and conclusions

The quality of the economic methodology has some potentially serious limitations, mainly because the authors caution that these costs are ‘are a general rather than an absolute guide’ (p444). This is a result of difficulty in getting accurate financial information due to differences in calculating costs and different funding streams across the 5 boroughs.

This is not a geographically representative survey and so findings should not be generalised to the rest of the UK. Furthermore, findings are specific to a group of individuals with learning disabilities and challenging behaviour with the highest cost care packages.

In summary, the authors find that the boroughs had ‘no consistent pattern of decision making or guidelines attempting to define who should remain or leave the boroughs’ (p444). However, individuals with higher and more complex needs were more likely to be placed out-of-area. Authors suggest that funds for out-of-area placements be used to develop services in-area.

Joyce T, Ditchfield H, Harris P (2001) Challenging behaviour in community services

Review question(s): 1.1, 1.3

Organisations the authors are involved with:
1. Services for Adults with Learning Disabilities, South London and Maudsley NHS Trust, London, UK

2. Cardiff Institute of Higher Education, Faculty of Health and Community Studies, Psychology Centre, Cardiff, UK

Type of study: Survey

Population: Adults with intellectual disabilities and behaviour that challenges

Country: UK

Quality score: +

Background and methods

Joyce et al. (2001) undertook a population-based survey of individuals with intellectual disabilities living in 3 London boroughs (n=448) to investigate the characteristics associated with out-of-area placement. These 3 boroughs were part of a large hospital closure programme so none of them had hospital provision of services. They developed specialist challenging behaviour teams, which worked with residential and day services.

Findings

The study found that individuals were more likely to be placed out-of-area if:

- they had aggressive and damaging behaviour,
- were male,
- black,
- young (<25 years),
- lived in a particular borough.

The authors speculate that the higher number of younger people in out-of-area placements may be due to lack of proper organisation and transition planning. Likewise, disproportionate placement of black people in out-of-area may be due to discrimination or inaccurate census data which underestimate the total number of individuals. If it is discrimination, the authors suggest provision of culturally sensitive services. Boroughs also had differential response, which could be attributed to a commitment or a skills issue. The borough that had the highest requirements for quality of staff training had the lowest number of out-of-area placements.

Considerations and conclusions

The findings from this study are applicable but cannot be generalised to the rest of the UK. This is a good quality population-based survey. In summary, improvements in local planning are needed to meet the needs of individuals with challenging behaviour.

Kozma A, Mansell J, Beadle-Brown J (2009) Outcomes in different residential settings for people with intellectual disability: a systematic review

Review question(s): 1.1 ,additional economic analysis on housing

Organisations the authors are involved with: University of Kent, Tizard Centre, Canterbury, Kent, United Kingdom

Type of study: Systematic review

Population: Adults with intellectual disabilities

Country: UK

Quality score: +

Background and methods

Kozma et al. (2009) undertook a review of research between 1997 and 2007 to explore the effects of different residential models on outcomes for individuals with intellectual disabilities.

Findings: included studies

A total of 68 studies were identified, of which 49 focused on deinstitutionalisation and the remaining compared different forms of community residential settings. The review included qualitative and quantitative studies and most were quantitative and the results are synthesised narratively. Study design of included studies were mainly cross-sectional (27 studies), longitudinal (23 studies) or both (18 studies). Included studies' time horizon ranged from 1 to 14 years. Most studies had a sample size larger than n=100.

Findings:

1. Community presence and participation

For the outcome of community presence and participation, 3 studies found that individuals in small-scale community housing had greater levels of participation than in larger settings and likewise another 3 studies found that individuals in semi-independent or supported living arrangements had greater levels of community integration than 'traditional' residential housing arrangements (p195). However, the studies note that some of the improvements are due to the quality of service supports and individuals' characteristics (in particular, greater adaptive behaviour, level and complexity of needs and individual's level of social competence) (p195). The implication is that while housing arrangements did have a positive effect, we do not know the precise magnitude of effect.

2. Social networks and friendship

For the outcome of social networks and friendships, 9 studies were identified. They found that individuals had more friends if they were living in small settings and with low staff turnover (p195). Likewise, individuals in supported living arrangements were more likely to know their neighbours, have visitors and have friends outside the home (p195). Again, the results can be interpreted to mean that while these settings had a positive effect, the magnitude of effect is also partially explained by setting characteristics (in particular, the use of active support) and individual characteristics (in particular, greater adaptive skills and lower levels of challenging behaviour) (p196). For the outcome of loneliness, while the hypothesis was that individuals in dispersed living would be at greater risk for loneliness, the review authors did not find evidence of this (p196). Instead, predictors of loneliness were feeling unsafe in the community and the lack of compatibility between residents, which is more likely in larger settings (p196).

3. Family contact

For the outcome of family contact, the review authors find that family contact was not related to type and size of housing arrangement, rather, predictors of contact included distance from family home and the individual's characteristics (in particular, ability, and both the service user and parent's age) (p196).

4. Self-determination

For the outcome of self-determination, the review authors found that smaller settings that were more individualised led to greater choice and opportunity for self-determination than larger, congregate housing arrangements (supported by 8 studies), but important predictors were staff working practices (empowerment and use of active support) and service characteristics (such as a home-like environment). Individual characteristics such as greater adaptive behaviour and lower levels of disability were associated with greater self-determination (p199). The review authors also found that individuals usually did not have choice over important decisions, including where to live and with whom to live (p199).

5. Quality of life

For the outcome of quality of life, the review authors found that in the move from institutions to the community, quality of life generally improved, although there was variation depending on individuals' characteristics, settings and staff practices.

6. Adaptive behaviour

In terms of adaptive behaviour, on the whole, evidence shows that those moving into the community from institutions were no different or improved and those individuals remaining in institutions were more likely to experience a decline in adaptive behaviour. Evidence also shows that those who had initially lower levels of adaptive behaviour had the greatest gains when moving from institutions and into the community compared to those with initially higher levels of ability. However, some studies found that other predictors of adaptive behaviour were service factors (including small residence size, stimulation of the home environment, the opportunity to make their own choices and staff working practices, such as teaching individuals skills, use of active support and increasing service users' independence) (p204).

7. Challenging behaviour

In terms of challenging behaviour, 6 studies found no differences after moving from institution into the community, although these studies were conducted pre-2004; 2 studies found that challenging behaviour increased; and 3 studies found mixed results, showing no differences when using standard measurement tools, but when using observation, there were decreases in certain types of behaviours (p204). One study suggests that staff paid more attention to challenging behaviour than to appropriate behaviour, and this was true across both institutional and community settings, and that challenging behaviour was more likely to occur with the absence of staff attention (p204).

8. Health and risk factors

In terms of health and risk factors, there is limited research around health outcomes for different housing arrangements. Overall, levels of inactivity and obesity were high. The review found that the probability of inactivity decreased with less restrictive settings but probabilities for smoking, poor diet and obesity increased (p209). The review authors noted that studies of mortality were common in US studies, which had mixed results. One author suggested that higher risk of mortality may be related to access to healthcare services (p209).

Conclusions and considerations

In conclusion, the studies within this review were not based on randomised designs so we cannot be confident about the included studies' findings. However, 'second-best' research designs were included, such as cross-sectional designs using matched comparison groups or regression analyses (27 studies), longitudinal studies using pre-post design with or without comparison groups (23 studies) and studies that used both designs (18 studies) (p194). The strengths of the studies are large sample sizes (42 studies had sample sizes greater than n=100). A limitation of most included studies is the use of convenience samples rather than a representative sample (p195).

The authors find that, for individuals with learning disabilities, while outcomes have generally improved by living in community, there is still variation in outcomes across various community settings. For instance, community participation, social networks and choice and self-determination vary according to individual characteristics like adaptive behaviour, but where services provide appropriate support to individuals with lower levels of adaptive ability, these can be improved, which is especially important for individuals with challenging behaviour. This is particularly important because while most studies show that challenging behaviour did not change in the move to community settings, community settings' environments have more demands and stimulation, which may require support in adapting to new situations. However, this can be done with the range of service and staff interventions available for individuals with challenging behaviour.

This review is limited in that the authors did not undertake a complete assessment of included studies' quality. This review described included studies' design and whether methods were used to control for confounding (such as individual characteristics). However, authors do not appear to undertake an assessment of studies' quality using a predefined checklist. However, the review authors do provide sufficient information about the included studies' design such that an indication of study quality can be gathered. Another limitation is that this review did not provide sufficient detail on included studies' sample characteristics, making it difficult to understand to which groups the findings apply (for example, whether included studies were specific to or included individuals with challenging behaviour).

Lindsay WR, Holland AJ, Carson D, Taylor J L, O'Brien G, Steptoe L, Wheeler J (2013) Responsivity to criminogenic need in forensic intellectual disability services

Review question(s): 1.1

Organisations authors are involved with:
1. Castlebeck, Darlington, UK
2. Bangor University, Bangor, UK
3. Deakin University, Melbourne, Victoria, Australia
4. Department of Psychiatry, University of Cambridge, Cambridge, UK
5. Department of Psychology, University of Abertay, Dundee, UK
6. Northumbria University, Newcastle, UK
7. Department of Psychology, NHS Tayside, Dundee, UK.

Type of study: Retrospective case note review comparing 3 types of services

Country: UK

Population: 197 people using forensic services across a catchment area of around 12 million people or a fifth of the UK population; 168 were male and 29 female

Quality score: +

Background

Type of service: generic community services: 15 community teams across 2 large geographical areas (total population 5 million); specialist forensic community intellectual disability (ID) services: 2 services; general inpatient units (5), low secure unit (1 regional and 1 small local service); medium secure units (1 large regional); high secure forensic ID services (2).

Aim of the study

To compare specialist forensic services to general community and secure services and to find out if these services provide appropriate treatment for people who use these services.

Reasons for referral to a service:

- 42% physical aggression,
- 26% verbal aggression,
- 14% contact sexual offences,
- 13% non-contact sexual offences,
- 20% property damage,
- 5% cruelty or neglect to children,
- 5% for alcohol/substance abuse,
- 5% theft,
- 3% arson.
- 75 (38%) had violence as an index offence and 62 (31%) with a sex offence as an index offence.

About the service

In this study, ‘generic community services’ refers to community learning disability teams which had a history of accepting individuals who had committed offences or showed signs of offending behaviour. Inpatient services were staffed by ID nurses, a psychiatrist and a psychologist and had access to speech and language therapists, occupational therapists and dieticians so were also considered to be specialist services.

The following number of people were referred to each type of service in the year 2002:

- community general n=77,
- community forensic n=53,
- inpatient n=16,
- low secure n=18,
- medium secure n=17,
- high secure n=16 (because of low referral rate, 2001 and 2002 were included), total n=197.

Findings

The most frequently referred forensic problems were violence and sexual offending. The authors compared the number treated for these 2 types of forensic problems provided by each different type of service.

Community forensic services and inpatient services provided appropriate treatment for 89% of referrals for violence and sexual offences, compared to only 9% of referrals receiving appropriate treatment by general community teams and 27% for secure services.

The study finds that specialist services are more likely to provide appropriate treatment services compared to generic community services and secure services for this group.

Considerations

The data used in the study is now 15 years old and services are likely to have been developed since this study. It is worth noting that the general community services in this study were chosen because they had some experience of dealing with forensic referrals, so you might expect the difference in outcomes between general services and specialist services to be less, so the finding that the difference is quite strong indicates that it might even be stronger if general community services with no experience at all of people with forensic needs were taken into account.

Mansell J, Beadle-Brown J (2004) Grouping people with learning disabilities and challenging behaviour in residential care

Review question(s): 1.1, additional economic analysis on housing

Organisations the authors are involved with: University of Kent, Tizard Centre, Canterbury, Kent, United Kingdom

Type of study: Systematic review

Population: Adults with intellectual disabilities and behaviour that challenges

Country: UK

Quality score: −

Background and methods

Mansell and Beadle-Brown (2004 −) review the literature on the effects of grouping individuals with learning disabilities by similar functionality. Functional groupings include those who are non-verbal, non-ambulant, have severe challenging behaviour, severe social impairment or are verbal and ambulant. We only report results for individuals with learning disabilities and challenging behaviour.

Findings

One study in this review, Emerson et al. (1992), found that there were no improvements in outcomes among individuals with severe challenging behaviour when they were moved from institutional care to congregate small group homes in the community. Another study in their review, Mansell et al. (1995, 2001) found similar results, where individuals with severe and profound learning disabilities and very serious challenging behaviour had worse outcomes in congregated homes than those who lived in specialised and mixed homes. The review authors do not specify which outcomes were made worse. Robertson et al. (2002) was included in this review (and was identified within the guideline systematic review – we summarise the results in the following section). They conclude that individuals in congregate settings had poorer outcomes than those in mixed, non-congregate homes.

Mansell et al. (2003) (n=303) compared individuals with learning disabilities with various needs living in congregate (75%+) vs. non-congregate (<75%) settings. Data were taken from individuals living in 68 small homes in England provided by the voluntary sector. Average number of residents was 6.5 (range =2–14) with an average of 0.65 staff to resident ratio (range= 0.3–3.1). In a simple group comparison, they found that individuals with severe challenging behaviour living in congregate homes received lower standards of care in relation to interpersonal warmth, assistance from staff, level of speech and staff teamwork. To increase the confidence in the findings, matched-pairs comparison was undertaken. This analysis found that individuals with severe challenging behaviour in congregate settings compared to those in non-congregate settings had lower standards of care as rated as by lower interpersonal warmth and team coordination. This study also undertook regression analysis and found that 13 of 15 items measuring the quality of staff support were worse for individuals with challenging behaviour in congregate settings. However, other service factors were identified as being predictive of better scores, including staff seniority, numbers of residents, management training, length of service, turnover and training in active support. A follow-on study using the same data measured the impacts on service standards on co-residents of individuals with challenging behaviour by comparing individuals who lived with none, at least 1, or with 75%+ of co-residents having challenging behaviour. The analysis found that living with people who have challenging behaviour did not have an effect on the same 15 service standards measured earlier. It is important to note that service standards are not the same as quality of life measures or other individual-focused outcomes. Therefore, the effect on co-residents' quality of life is unclear and requires research.

Considerations and conclusions

In total, 4 studies in this review lend supporting evidence that individuals with challenging behaviour do worse in congregate settings than they do in non-congregate (mixed) settings, where 'congregateness' is measured as 50 to 75% of percentage of individuals with challenging behaviour in a home.

This review is limited because it did not report its search strategy, methods for assessing included studies' quality, and did not report methods for data extraction.

These limitations prevent us from being confident in the reliability of the authors' findings. Another limitation of the review is that included studies based on older data (published pre-2002) and we advise caution before generalising findings to today's context.

Mansell J, Beadle-Brown J (2009) Dispersed or clustered housing for adults with intellectual disability: A systematic review

Review question(s): 1.1, 1.3, additional economic analysis on housing

Organisations the authors are involved with: University of Kent, Canterbury, Kent, United Kingdom

Type of study: Systematic review

Population: Adults with intellectual disabilities

Country: UK

Quality score: −

Background and methods

Mansell and Beadle-Brown (2009 −) undertook a review on the quality and costs of ordinary housing dispersed in the community compared to housing clustered together to form a separate community (including, village communities, residential campuses or clusters of houses) for individuals with intellectual disabilities.

The authors review the theoretical arguments for and against each type of housing model. Some argue that dispersed housing is advantageous because it provides opportunity for integration into society. Others argue that clustered housing can provide the same potential for integration but could also increase individuals' social lives, increase safety and lower costs due to economies of scale. They also argue that dispersed housing could put individuals at greater risk of abuse and exploitation.

Definitions of ordinary dispersed housing include apartments and houses of the typical size and type as those found in the general population. The authors note 2 main types of dispersed housing: small group homes where a small number of individuals live together and receive staff support and both support and accommodation are provided by a single service provider. Second, ‘supported living’ where individuals rent or own their own accommodation and receive staff support from a selected agency and they decide with whom they will live.

Definitions of clustered housing are several. A village community is self-contained intentional community made up of, frequently, unsalaried support workers and families living communally and provides a social and cultural framework. Residential campuses are another type of clustered housing, are also self-contained and provide services on site – however, this is typically provided to individuals with higher support needs and support staff are usually paid. Cluster housing is another type where several small houses are located in the same area. It is important to note that institutions are very similar to residential campuses although they were much larger in scale.

Findings: included studies

The review authors identified 19 studies, of which 14 were in the UK, 1 from the UK and Ireland, 2 from Ireland, 1 from the Netherlands and 1 from Australia. Nine studies used data from the same study, comparing n=500 people in village communities, NHS residential campuses and dispersed housing. In total (and excluding duplications from the same study), findings are based on experiences of n=2500 people from 10 different studies. Fifteen studies were cross-sectional, 3 were longitudinal, and 1 was qualitative. Six studies reported on costs but they drew on 3 different studies.

None of the studies were randomised. Five studies undertook a matched comparison while other studies used statistical methods to control for differences between individuals across settings.

The number of people living in dispersed housing was usually 8 or fewer; in 1 study this was up to 16 residents. Clustered settings with a minimum of 100 places occurred in 11 studies; in another 5 studies, this was between 20 and 55 places. Three studies did not report this information.

1. Findings on outcomes

The review found that, overall, dispersed housing performed better across many more outcome domains than did campus/clustered housing.

For the outcomes of social inclusion, interpersonal relations, material and emotional wellbeing, cluster housing either did worse or was not different to dispersed housing. The only exception is village housing, which had better or did no differently than dispersed housing for various measures of interpersonal relations, physical wellbeing, medication, safety and certain types of health checks. However, in more areas of health screening, cluster/campus housing did better or was no different than dispersed housing.

For the outcomes of self-determination, personal development and rights, cluster housing either did worse or was not different to dispersed housing.

For the outcomes of home-likeness, environmental quality and number of people sharing the home, cluster housing did worse than dispersed housing.

For the outcomes of social climate and working practices, cluster housing mostly did worse and in some areas was not different to dispersed housing. The only exception is village housing, which had better outcomes for some measures of social climate and working practices when compared to dispersed housing.

For the outcomes of staff ratio and staff contact and assistance, cluster housing did worse or was not different to dispersed housing.

For the outcome of staff care (general), there were no differences between village and dispersed housing. Two other studies had mixed results, with 1 favouring campus housing and the other favouring dispersed housing.

2. Findings on costs

In relation to costs, 1 study found that dispersed housing cost more than campus housing, but this was due to higher staffing ratios in dispersed housing (citing Hallam et al. 2000). However, when costs were adjusted for differences in staffing level, there costs were similar. This was found in 2 studies, of which 1 compared specialised dispersed housing to specialised campus-based time-limited further educational service (citing Hatton et al. 1995) and the other undertook a matched comparison of people in village communities to those in dispersed housing and also a matched comparison of campus housing to those in dispersed housing (citing Emerson et al. 2000).

Conclusions and considerations

The limitations of the findings are that most studies are cross-sectional so it is unclear whether outcomes or costs change over time between settings. Another limitation is whether differences in outcomes are inherently due to setting design or whether it is due to poor management and organisation. However, this seems unlikely given the large body of evidence from several countries indicating that, on the whole, outcomes were mainly worse or in some cases not different to dispersed housing. They conclude that while cluster housing had lower costs than dispersed housing, this was due to lower staffing levels and the authors conclude that while cluster was cheaper, they provided worse outcomes on a majority of measures. On the other hand, village community was an exception.

The review is limited by the use of narrative synthesis, not reporting the quality of included studies, making it difficult to assess the reliability of the findings, and not providing detailed information about sample characteristics, making it difficult to generalise findings. Furthermore, the review includes all adults with intellectual disabilities and was not specifically focused on individuals with challenging behaviour, although they may have been included.

McConkey R, Gent C, Scowcroft E (2013) Perceptions of effective support services to families with disabled children whose behaviour is severely challenging: a multi-informant study

Review question(s): 1.4

Type of study: Qualitative study of views and experiences

Country: UK

Population: Children

Score: ++

Background

This study aims to find out if intensive support services available to families whose children (up to 19 years of age) have a learning disability and behaviour that challenges meets the needs of the families. Two forms of support are provided by these services. Short breaks in a small residential home and community support services where staff will come to the family home and take the young person to activities in the local community and provide advice and training to the family in managing challenging behaviours.

The services were all provided by the same provider, but in 3 different cities in the UK. Seventeen children were randomly selected from children currently receiving the service or who had received the service in the past 2 years for the study.

Interviews were held with parents or family carers, key workers within the service and with professionals (mostly social workers) who had referred families to the services. The people doing the interviews were experienced researchers, not involved in providing the services.

The key themes that came out of the interviews about intensive support services that are important to families include the following.

- Access to services: the need to balance access to the service between emergency placements and prior bookings and the need to have services available for children with different levels of independence.
- Family life: both parents and other siblings can get more one-to-one time together and uninterrupted sleep when using the short-break service.
- The future: there was a lot of concern from the different groups interviewed about what will happen when children reach the age that they have to move into adult services and whether the same intensive support services will be available. For some young people, it seemed that some form of residential provision would be needed as the family was unlikely to cope.
- Impact on carers: for family carers, getting involved with social events provided by the services meant meeting other parents facing similar challenges and they could see the positive benefit from using the services and not feeling like they had failed.

- Inclusion/social interaction: one of the big benefits to children and young people is they get more social interaction with other people and are able to take part in community activities when using the service.
- Respite care: some families in the study had 2 or more children with disabilities. While provision of short breaks for 1 child helps it doesn't give parents a complete break.
- Staff skills: another big theme from the interviews is that good relationships with the way staff worked with families and other services, is central. It was particularly important that people that work in the short break services build relationships with the children's parents. Main themes included: being non-judgemental, committed, confident and consistent.
- Knowledgeable staff that could share their expertise with families was another related theme.

While there are many benefits for families from these short break services the children and young people who use the services are reported to benefit more.

Findings

The authors suggest that parents have mixed emotions when it comes to accessing these kinds of services. Parents and carers were less optimistic when the conversation turned to the future. There are concerns that the current climate of austerity may not invest in such services when children become adults, however failure to invest may lead to higher costs in the long term.

The authors conclude that short break services can make a big contribution to children who are challenging staying within their families. But this will only happen if the complexity of family situations is managed, trusted relationships are formed and the benefits for the child and family are identified.

One of the limitations of the study is that the services provided in people's homes is not well reported. This could have been because more people used the short breaks service.

McGill P, Poynter J (2011) How much will it cost? Characteristics of the most expensive residential placements for adults with learning disabilities

Review question(s): 1.3, additional economic analysis on housing

Organisations the authors are involved with:

1. Tizard Centre, University of Kent, England

2. Department of Health, England

Type of study: Survey

Population: Adults with intellectual disabilities who have the most expensive placements

Country: UK

Quality score: −

Background and methods

McGill and Poynter (2011 −) undertook a descriptive analysis of the costs and characteristics of the highest-cost placements for individuals with intellectual disabilities. Data were based on 70 individuals from 14 local authority areas in the South East region of England between 2009 and 2010.

Findings on characteristics

A total of 71% of the sample lived in out-of-area placements. Individuals in out-of-area placements, compared to in-area placements, were more likely to be male (80% vs. 55%), in residential care (72% vs. 35%) and not in supported living (2% vs. 45%). There were no differences between in- vs. out-of-area placements with regards to cost or other individual and placement characteristics (number of individuals with discharge dates, individual plans).

Findings on costs

The mean placement cost was £172,000/year. The mean cost per local authority ranged from £98,000 to £250,000/year. Predictors of higher costs were for individuals in hospital or similar settings (£219,000 vs. £161,000/year), for those with challenging behaviour (£190,000 vs. £157,000), people with specific syndromes (£223,000 vs. £168,000), higher severity of learning disability (£181,000 vs. £149,000) and younger age (costs not provided).

Conclusions and considerations

This survey has several limitations due to a lack of reporting and methodology. There is no detailed information about the survey provided, response rates, whether all individuals are included (for data collection) and methods and analysis are not reported.

Furthermore, the generalisability of the findings are limited due to the date of the survey and that findings are based on specific locations in the South East of England.

National Association of Adult Placement Services (2009) A business case for Shared Lives

Review question(s): 1.3, additional economic analysis on housing

Organisations the authors are involved with: National Association of Adult Placement Services

Type of study: Economic evaluation

Population: People using Shared Lives

Country: UK

Quality score: −

Background and methods

NAAPS (2010) is an organisation that represents Shared Lives and they produced a report highlighting the business case for the Shared Lives scheme. The report introduces and describes the Shared Lives scheme and provides statistics on uptake in England in 2009. The report also provides a selection of quotes from service users from the CQC inspection reports but it is unclear whether these are from individuals with learning disabilities. Quotes are also provided from Shared Lives carers and Shared Lives scheme workers.

Findings

The report categorises the responses from service users, carers and scheme workers into the areas of choice and control, flexibility and individualisation, supporting people in monitoring and responding to health needs, developing confidence, skills and independence, risk management, and fairness and opportunity. In these areas, responses were positive.

In the area of Shared Lives carers' experiences of being supported by the scheme workers, some comments indicated that support is sometimes underprovided, and that some carers made sure to vocalise their needs in order to get appropriate support from the scheme (NAAPS 2010: 13). At the time of this report, another area that needed improvement was increasing the transparency, fairness, and timeliness of tariffs paid to Shared Lives carers, as this varied across schemes (NAAPS 2010: 14).

Costs

The NAAPS (2010) report provides a financial analysis of setting up and maintaining a Shared Lives scheme. While the methods are not clearly reported, the authors find that a service staff team with 0.8 FTE managers, 3.3 FTE placement workers and 0.7 FTE administrators provide a good quality service to 85 service users, 55 Shared Lives carers and 120 placements (NAAPS 2010: 17). It is reported that it takes between 11 and 16 months to develop an operational Shared Lives scheme. The authors also provide estimates for potential cost savings arising from the substitution of community residential homes with the use of Shared Lives. However, these estimates are for individuals with learning disabilities in general, and it is not clear whether these are applicable to individuals with challenging behaviour. In light of this caveat, it is estimated that savings of £640/week could be made for an individual with learning disabilities living in residential care and a savings of £995/week for an individual in semi-independent living arrangements (2009 prices) (NAAPS 2010: 20). Under such a scenario, the authors report cost savings are likely to occur in the second year of operations, after covering the staffing and administrative costs of the

Shared Lives scheme (NAAPS 2010: 21). A limitation of the estimated costs of Shared Lives is the exclusion of costs related to insurance, office equipment and supplies, operational costs and travel (NAAPS 2010: 17). Including these items would increase the cost, but the precise magnitude is not clear, meaning it is not clear whether cost savings would still occur in the second year. The estimated costs of the Shared Lives scheme are the same as those reported in the summary of the PSSRU Unit Costs (2011) report (above).

The report then goes on to describe the potential advantages and disadvantages of a scheme operated by a local authority or by an independent organisation, or a partnership between both (NAAPS 2010: 22). The report also describes sources of funding and service users' financial contributions (NAAPS 2010: 23–4).

Conclusions and considerations

This report is limited by not reporting the source of unit costs for the estimation of Shared Lives staffing costs. It is also limited as it only captures part of the total costs of providing Shared Lives. In particular, it only calculates staffing costs but did not include capital/building, insurance, office equipment, supplies, travel and operational costs).

Pearson G (2012) The transition experience of developmentally impaired young adults living in a structured apartment setting

Review question(s): 1.4

Type of study: Qualitative study of views and experiences

Country: USA

Population: Adolescents

Quality score: −

Background

The questions the study asked were:

- What is it like to move into independent living if a person is developmentally impaired, with behaviour problems that need psychiatric care?
- What is the lived experience of adolescents with pervasive developmental disorder (PDD) who have moved into a supervised apartment setting with an associated adult services model of care?
- How do they think about their current functioning and the process of their moving into independent living?

The researcher worked with another research assistant to compare notes taken at the interviews and all activities were recorded carefully. The researcher who did the interviews was very experienced in working with people who had PDD.

Their findings were given to the case manager to pass on to the people who gave the interviews, but they weren't allowed any more contact with them afterwards, so they could not have had any feedback from the people who took part.

The question the researcher asked them to start the interview was about what their experiences were in growing up and they answered in their own words. The interviews were tape-recorded and lasted between 35 minutes and an hour.

The authors looked at everything that people said and found groups of answers around:

- living environment,
- presentation of self,
- personal history,
- relationships with others.

We found that there were things that people said that could be grouped into themes that we have learned from other studies.

1. Access to support

Most people had said that they had been psychiatrically hospitalised or placed in residential care in the past.

2. Choice and control

Most of the participants said that they had mixed feelings about residential care and currently 8 out of 10 said they were depressed or dissatisfied about their living situation and this was often to do with lacking choice and control. For example, people said that they felt having to rely on or ask staff to do things for them that they felt they could do on their own was frustrating.

3. Environment

The study said that most of the apartments were run down and/or dirty and that people who lived there didn’t seem to have much emotional connection to them.

4. The future

Most of the participants didn’t really talk about their plans far into the future, and when they did it was about planning to be independent of the programme. One person said that they wanted to leave the apartment to be on their own, as this arrangement wasn’t really like real life.

5. Health and wellbeing

Participants often reported poor physical health, including being very overweight. Sometimes this was due to the side-effects of medication which could also affect concentration.

6. Inclusion/isolation

Four of the participants had room-mates, but did not have particularly good relationships with them. Only 2 reported having a romantic interest. Six of the 10 participants said that they didn’t have a particularly good relationship with their family. People who took part in activities outside of the home, like being employed or volunteering, were not especially enthusiastic about them except for the person who worked at a restaurant, a job he found on his own, and he was praised for his work by his supervisor.

7.Staff skills

There were mixed reports about staff – 4 participants said they found help with budgeting helpful, 2 found staff intrusive, whereas 1 thought they were not available enough.

Overall the authors conclude that people found the process of growing up and becoming independent was a mix of positive and negative experiences such as on the one hand a sense of loss of support, and changing relationships with families, but on the other hand a sense of freedom, independence, asserting one’s rights and a feeling that they were growing up.

The authors say that their findings show the importance of planning for all aspects of wellbeing, and shows that there is need for people to be involved in planning their own care.

Considerations

People who took part were selected by case managers based on their willingness to take part. The researchers did not know how many people had been asked if they would like to participate and what proportion actually agreed or for what reasons the case managers made their selection. But the case managers said that the people who agreed to take part were representative of people in the home more generally.

It might be that the people who said yes to taking part were more keen than others in that they had something to say, or there might have been reasons that we don’t know why some people said they didn’t want to take part – which means that the sample wasn’t representative. This is a problem is called sampling bias, but it is very common in qualitative research and difficult to overcome.

We think this study is based in the USA because the author is from the University of Connecticut School of Medicine, although the paper doesn’t say this. There may be issues on how similar the services may be to the UK, although young people’s experiences of growing up and learning to live independently could be assumed to be similar in many countries.

Perry J, Allen D, Pimm C et al. (2013) Adults with intellectual disabilities and challenging behaviour: the costs and outcomes of in- and out-of-area placements

Review question(s): 1.1, 1.3

Organisations the authors are involved with:

1. Welsh Centre for Learning Disabilities, School of Medicine, Cardiff University, Cardiff, UK

2. Abertawe Bro Morgannwg University Health Board Directorate of Learning Disability Services, Bridgend, UK

3. Health Economics and Policy Research Unit, University of Glamorgan, Pontypridd, UK

Type of study: Comparative economic evaluation – compares 2 different types of services and looks for similarities and differences in costs and outcomes

Country: UK

Population: Adults with intellectual disability and behaviour that challenges

Score: −

Background

The aim of this UK study was to compare the costs and outcomes of people living in-area vs. out-of-area placements. This study focuses on (N=76) adults with learning disability and challenging behaviour with mixed level of needs.

Individuals living in in-area placements were older and had higher levels of mental health problems. In-area residents had slightly lower adaptive behaviour and higher levels of challenging behaviour. Both had greater proportions of men living in the residence.

In terms of residence, in-area placements had twice the levels of staffing hours per person per week and smaller number of residents living within the residence (3.5 people, range =1–12, sd=2.21, vs. 8.5 people, range =1–24, sd=6.4; $p<0.01$).

Findings

In-area placements were better in many more aspects of both quality of care and quality of life. However, in many areas, both settings had similar outcomes. Out-of-area placements only did better in few areas.

In-area placements were better in relation to quality of care, as measured by:

- greater use of behavioural assessment and teaching,
- greater staff training and supervision,
- residential experience.
- Staff were less likely to be ‘distant’.

Methods/measures in the treatment and control of challenging behaviour:

- staff used less physical restraint,
- staff used functional analysis more often,
- quality of life, as measured by independence in the community,
- higher number of activities in the community in the past month,
- size of social networks,
- greater number of visits from family and friends in the past 3 months.

Out-of-area placements were better in relation to:

- methods in the treatment and control of challenging behaviour,
- staff using sedation less,
- health,
- greater number of vision checks,
- larger percentage being active.

Both settings were not different in relation to:

- 2 measures of lifestyle satisfaction,

- safety,
- sense of social isolation,
- range and frequency of social and community activities,
- choice,
- independence of participation in domestic management,
- methods in the treatment and control of challenging behaviour,
- use of seclusion and other techniques,
- use of written programmes,
- use of medicines review,
- use of usual interventions, including:
    - no intervention
    - ignore the behaviour as part of an agreed programme
    - verbal response
    - physical intervention
    - health
    - BMI
    - health checks including general checks, blood pressure, dentists, and hearing
    - healthcare and lifestyle scores.

Cost-effectiveness

- In-area placements cost more in comparison to out-of-area placements. This is because of higher accommodation and non-accommodation costs.
- In-area accommodation costs were higher due to higher staffing costs and slightly higher non-staff costs (administration and overheads).
- In-area non-accommodation costs were higher because of higher daytime activity costs and hospital services. However, the provision of hospital services may have been due to availability of a highly specialised centre in that area. Both in-area and out-of-area placements had similar use of community healthcare services.
- Cost of travel to families was 4 times higher for those in out-of-area placements compared to in-area placements.
- Costs included health and social care services. Price year is 2008/09.

We are concerned about the quality of the economic methods. This makes it difficult to be confident about the findings on costs. We are particularly concerned with accommodation costs, which were based on local prices, which means that it is unclear whether differences in accommodation costs between in-area and out-of-area placements were due to differences in resource use or local prices. We are not concerned about non-accommodation costs. These methods were good.

Considerations

This study is of low to moderate quality. This is because the study does not use a randomised design. This is important because a good study design helps us be sure that the outcomes and costs are a result of differences in the services provided, and not due to other factors, like individual characteristics.

The authors tried to make the study design as good as possible, even though it was not randomised. They did this by trying to match the groups as much as possible on levels of challenging behaviour. However, the samples were different in other ways (as mentioned earlier).

However, the individuals were not exactly the same. This means that differences in outcomes and costs are not entirely due to differences in the services they received. It may have been influenced by other factors. We don’t know how much results would change if this had been a randomised design study.

Furthermore, the results cannot be entirely attributed to the difference in location. This is because the services were different in other ways. This means that these other differences could have affected outcomes and costs.

Pratt K, Baird G, Gringras P (2012) Ensuring successful admission to hospital for young people with learning difficulties, autism and challenging behaviour: a continuous quality improvement and change management programme

Review question(s): 1.4

Types of study: Qualitative study of views and experiences

Population: children

Country: UK

Quality score: −

Background

The authors say that the experience for families and children who have autistic spectrum disorder (ASD) and behaviour that challenges who are having to be admitted to hospital can be distressing, uncomfortable and can lead to increased behaviour that challenges, additional nursing staff input and use of medication.

The audit aims to see if these experiences can be prevented by planning ahead of the admission and providing a key, named link person to help make the pre-planning assessment, in this case a very experienced outreach nurse, who would also identify a key named person to take care of the families when the child was admitted.

The authors interviewed 20 members of staff and 8 parents from 4 families.

We grouped what people said into the themes that we had found in other studies.

1. Barriers

Parents said they experienced practical barriers to good care.

Car parking: ‘no spaces outside the hospital or cannot park for more than an hour. We need the car to bring the child/young person to hospital as behaviour is too difficult for public transport’. (p792)

‘Our child is not able to wait around for long periods.’ (p792)

‘We are anxious about the noise of the ward and how our child will react.’ (p792)

2. Facilitators

Facilitators for parents
Parents/carers preferred the pre-planning assessment and more information was gained if it was completed in outpatients or during a home visit.

The authors asked families what might trigger behaviour that challenges – sometimes the children are very sensitive to noise, some may have rigid likes and dislikes, sensitivities to various stimuli or may have routines and rituals. If these can be determined in advance, then strategies can be employed to overcome this, such as providing a quiet cubicle to minimise noise (p791).

Facilitators for staff

The nursing staff felt it was 'extremely' useful to know in advance how best to cater for these children's needs.

Giving staff strategies and warnings about possible challenging behaviour and how to prevent it reduced the likelihood of any serious incidents occurring.

3. Personalisation of care

As noted, some children may have rigid likes and dislikes, sensitivities to various stimuli or may have routines and rituals. If care is personalised to the child then staff can think ahead for strategies to overcome these kinds of difficulties.

4. Staff skills

Nursing staff stated that they felt the challenging behaviour caused them anxiety. They felt deskilled, and that they had a lack of knowledge about ASD because of a lack of basic training. A need was expressed for additional staff who had mental health training.

Considerations

The methods of conducting the research wasn't very clear – for instance, how the families were selected to participate, how many were asked to give their view and how many agreed to take part. It wasn't always clear which person was being quoted so we do not know if only 1 person was speaking or if the quotes were from a range of people.

There were only 4 families, but the new checklist being used had only been used for a short period of time (1 month).

The authors do not say what methods they used to analyse the data or how many people were involved in checking each other's interpretation of what people said.

Robertson J, Emerson E, Pinkney L et al. (2004) Quality and costs of community-based residential supports for people with mental retardation and challenging behavior

Review question(s): 1.1, 1.3

Organisations the authors are involved with:

1. Institute for Health Research, Lancaster University, UK

2. Welsh Centre for Learning Disabilities, University of Wales College of Medicine, UK

3. Bro Morgannwg NHS Trust, Learning Disabilities Directorate, UK

4. Centre for the Economics of Mental Health, Institute of Psychiatry, UK

Type of study: Comparative economic evaluation – compares 2 different types of services and looks for similarities and differences in outcomes and costs

Country: UK

Population: Adults

Quality score: +

Background and methods

Definition: Congregate: In this case it means that most of the people in congregate settings are people with learning disabilities and behaviour that challenges. Non-congregate: In this study it means that most people in the home did not have learning disability and behaviour that challenges.

The aim of the study was to find out how the 2 different types of settings compared on costs and outcomes. It focuses on adults with severe learning disability and challenging behaviour. It was in response to the guidance that people with learning disabilities and behaviour that challenges don't do as well as those in non-congregate settings.

The study focused on adults between ages 18 and 65 years old. The average age was between 36 and 38 years old. Both settings had between 2 to 6 residents, with an average of 4 residents per setting. Both settings were located near ordinary housing for people without learning disabilities.

The method of analysis was a non-randomised, matched-group design (n=50). Data were taken from individuals across 36 settings provided by 20 different organisations in England and Wales.

Characteristics of study participants

Compared to individuals in congregate settings, individuals in non-congregate settings:

- had been living in their current placement longer,
- entered residential care at a younger age,
- had an equal split of males and females (whereas congregate settings had more males), and
- relatively higher percentages with mental health problems.

Individuals in congregate and non-congregate settings were similar in relation to percentage with autism and levels of adaptive and challenging behaviour.

Information was gathered by interviewing staff who knew the people really well. They also watched carefully and took notes on how people were around each other in the homes. They interviewed everyone twice at different times.

The study found some differences between the two groups. In summary, people in non-congregate settings had generally better outcomes in the methods that staff used to treat and control challenging behaviour and also had better quality of life outcomes. Both congregate and non-congregate settings had similar outcomes in relation to risks and injuries. Congregate settings did better on staff working practices, but these did not translate into better outcomes for individuals.

Specifically, people in non-congregate settings:

- had better outcomes for quality of life, as measured by higher hours of scheduled activity per week,
- had better outcomes for co-tenants, as they had higher numbers of community activities,
- said they had greater choice over aspects of their lives at the first interview, but this difference wasn't found at the second interview.

Non-congregate settings were not different from congregate settings in relation to risks and injuries, and this included 'actual accidents; reported risk of accidents; exploitation; abuse from staff, people in the local community, or ''others''; and the percentage of residents who had received serious or major injuries from co-tenants with both categories occurring at extremely low levels' (p339).

However, when combining the outcomes to include co-tenants, non-congregate settings had fewer minor injuries compared to congregate settings (44% vs. 15%, when measured at the second interview).

People in congregate settings:

- had worse experiences in terms of staff methods of treating and controlling challenging behaviour, this includes:
    - higher use of pharmaceuticals (at the second interview only)
    - higher use of physical intervention used sometimes or usually, and
    - higher use of physical intervention used by more than 1 staff member
- had a greater amount of non-negative staff contact,
- had better staff working practices such as:
    - person-centered planning
    - greater use of assessment and teaching
    - greater levels of activity planning
    - greater levels of staff support to residents.

However, these better outcomes for staff working practices did not translate into better outcomes for individuals. We can see this through the lack of differences or inferior outcomes experienced in congregate settings in relation to quality of life and methods for the treatment and control of challenging behaviour.

Further analyses were conducted to try and improve the comparison of congregate and non-congregate settings.

This second analysis found that congregate settings had:

- smaller social networks,
- higher staff ratios,
- less rigidity of routines,
- more block treatment,
- more depersonalisation,
- less home-like settings.

Findings on cost-effectiveness

Non-congregate settings cost less (£12,011 less) than congregate settings and this was due to lower accommodation costs (approximately £15,650 less), some of which were offset by higher use of community services through the use of day activity services (approximately £3,691 more).[9]

Price year for costs is not clearly reported but may be close to date of publication (2003/04). The costs are presented for a one-year period.

We are concerned about the quality of the economic methods. We are particularly concerned with the calculation of accommodation and non-accommodation costs. These costs were based on local prices, meaning it is unclear whether non-congregate settings were less costly because of lower prices or lower use of resource inputs. Based on the limitations of the economic methods it is not possible

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[9] Figures may not add up to £12,011 due to rounding resulting from USD/GBP conversion rates.

to determine whether in-area or out-of-area placements are relatively more cost-effective.

Considerations

This study is of low to moderate quality. This is because the study does not use a randomised design. This is important because a good study design helps us be sure that the outcomes and costs are a result of differences in the services provided, and not due to other factors, like individual characteristics.

The authors tried to make the study design as good as possible, even though it was not randomised. They did this by trying to match the groups as much as possible on levels of challenging behaviour. They even did additional analysis to improve comparison based on levels of challenging behaviour. However, the samples were different in other ways (as mentioned earlier).

Therefore, while the individuals are very similar in relation to challenging behaviour and adaptive behaviour, they were not exactly the same in other ways. This means that differences in outcomes and costs are not entirely due to differences in the services they received. They may have been influenced by other factors. We don’t know how much results would change if this had been a randomised design study.

Also, this study is nearly 10 years old and the policy landscape has changed since its publication date. The UN Convention on the Rights of Persons with Disabilities was adopted in May 2008 which obliges states to develop greater opportunities for community living and move away from congregated settings.

In the UK, the Department of Health’s 2012 report ‘Transforming Care’ states that:

‘... the norm should always be that children, young people and adults live in their own homes with the support they need or independent living within a safe environment. … People with challenging behaviour benefit from personalised care, not large congregate settings.’ (Department of Health 2012, p19)

Slevin E, Sines D (2005) The role of community nurses for people with learning disabilities: working with people who challenge

Review question(s): 1.4

Type of study: Qualitative study of views and experiences

Population: Community nurses in adult or children’s teams

Country: UK

Quality score: ++

Background

This was a good UK-based study that asked for the views and experiences of 22 community nurses who looked after people with learning disabilities and with behaviour that challenges. The authors were interested in finding out about how nurses’ viewed their everyday work. They interviewed the nurses face to face at a time and place that was best for them in 1 UK region (not specified).

We looked at what the nurses said about their work and we grouped these into the different themes that we learned about in other views studies.

Barriers

Nurses spoke about the lack of respite services available leading to the unintended consequence that general hospitals were used instead. They said this was the opposite of the commitment to community care.

Facilitators

Nurses said they were able to link the families up consultant psychiatrists, GPs and other professionals as well as other professionals and other resources in the community, in both the public and the voluntary sectors.

They said that a good quality relationship between them and the families they visited was an effective approach.

Access to support

As noted, nurses said that a lot of their work was liaising with and linking their client families to other professionals, like consultants, GPs and psychologists, in both the statutory and the voluntary sectors.

Defining behaviour that challenges

An important part of the nurses’ work was on ‘initial assessment’ to ‘identify and focus on cause’.

Inclusion/isolation

Nurses said that behaviour that challenges could lead to social exclusion, but also exclusion within services.

Personalisation of care

Nurses said that they often used a functional analysis approach with their clients; this is an approach that tries to understand the person’s behaviour from the person’s point of view and what they might be trying to communicate or what the behaviour achieves at the moment and if there are better ways to communicate instead.

Staff skills

Their view was that the role of nurses caring for people with behaviour that challenges should be recognised as specialist work.

Trust

The nurses often said that they saw having a trusting relationship with the families was an essential part of their job.

Working together

Working together was a theme that came up a lot. Nurses said that they saw it as their role to help families navigate services, and to empower families to speak up for themselves, to be better enabled to cope with behaviour that challenges themselves, and to be there to let families talk things over with them.

Considerations

Although qualitative research does not have its main aim to be representative, as quantitative studies do, it is still not clear that the experiences of these nurses will be similar in other regions of the UK, or whether the HSS (health and social services) region they worked for was particularly well or not well organised. There may be other organisational or geographical factors not known about this single UK region.

The authors also point out that it would have been good to include the views and experiences of the people with learning disabilities and behaviour that challenges and their families. The study might also have benefited from observing the nurses at their everyday work.

This is quite an old study (more than 10 years old) and the actual interviews with the nurses could have been done a year before publication, so this model of delivering care in people's homes may have changed. However, looking at more recent studies for this research question, both families and carers and people who access services still talk about similar types of things as the nurses did, so it could still be relevant to this review.

Stancliffe RJ and Keane S (2000) Outcomes and costs of community living: a matched comparison of group homes and semi-independent living

Review question: additional economic analysis on housing

Organisation the authors are involved with: University of Minnesota, USA

Type of study: Non-randomised comparison

Population: adults with intellectual disabilities and behaviour that challenges

Country: UK

Quality score: −

Background and methods

Stancliffe & Keane (2000) undertook a non-randomised comparison study in Australia (n=54) which compared individuals living in 3- to 7-person group homes (mean=4) with full staff during waking hours compared to individuals living in 1- to 4-person group homes in semi-independent living arrangements (mean=2.3) with partial staff support (maximum 28 hours of waking hours support per week).

N=27 individuals in group homes and n=27 in semi-independent living were selected and matched based on based on adaptive and challenging behaviour and other physical and mental health disabilities. Participants were recruited from 13 different accommodation and support agencies. Outcomes are measured at a single point in time and costs are calculated for a one-year period.

Individuals' level of adaptive behaviour was measured using the Inventory for Client and Agency Planning (ICAP) Broad Independence score, whereby matched individuals differed by no more than 5 points. Adaptive scores were (mean, (sd)), 490 (17), for individuals in semi-independent living, and 489 (20), for those living in fully-staffed group homes.

Challenging behaviour scores were based on the ICAP General Maladaptive Index whereby matched individuals differed by no more than 13 points. Challenging behaviour scores were (mean (sd)), -7.2 (5.3) for those individuals in semi-independent living, and -7.8 (6.5), for those in fully-staffed group homes.

Individuals were also matched on physical and mental health needs and other disabilities (autism, blindness, cerebral palsy, deafness, epilepsy, psychiatric diagnoses, chronic health problems).

The analysis compared individuals' self-reported outcomes for loneliness, safety, and quality of life.

Support staff were also asked to report on individuals' outcomes for personal care, domestic management, healthcare checks and lifestyle, money management, social network, number and frequency of mainstream community services in past 3 months, community participation, participation in domestic tasks, stability of place of residence, living companion turnover, and presence of natural support (regular (at least monthly) support from a person who was not paid to provide it).

Findings - outcomes

Findings from the analysis indicate that individuals in semi-independent living had either similar or better outcomes across a range of areas compared to similarly matched individuals in fully staffed group homes.

Individuals in semi-independent living had statistically better outcomes than those in fully-staffed group homes for the following outcomes:

- Quality of life, as measured by feelings of empowerment and independence ($p=0.02$)
- Community participation, as measured by higher frequency of community participation ($p=0.05$) and number of times they participated in the community without support staff ($p=0.01$).
- Participation in domestic tasks, as measured by greater independence in carrying out domestic tasks ($p=0.04$), in particular, preparing meals, washing up, and shopping for supplies ($p<0.01$).

There were no differences for the outcomes of: safety at home and safety away from home, personal care, domestic management, healthcare, money management, social contacts (family and friends), and living companion turn-over.

Findings - costs

The perspective of the economic analysis was that of the service provider. Therefore it only included costs related to housing, defined by four components:

- direct staff support to participants in the household,
- additional individual staff costs funded from participant’s individual funding,
- administrative costs, and
- other costs of running the service (rent and equipment).

Capital costs were not included. No information is available on individuals’ use of wider services (i.e. healthcare, day programs, and employment). Costs reflect the 1997/1998 year.

Limitations of the costing analysis include a lack of clarity around the source of unit costs, meaning it is unclear whether differences in total costs between settings are due to prices or differences in resource inputs.

Additional limitation is the inability to ensure that housing agencies were using the same methodology and definitions in reporting housing-related costs.

Furthermore, the authors note that there were differences in tenancy arrangements, which they believe poses another limitation in making a fair comparison of costs. For example, n=17 semi-independent individuals versus n=4 group home residents lived in ‘Housing Department’ accommodation which have lower rental costs than privately rented housing. As a result, the authors advise that a more fair comparison of costs would focus on staffing costs only. They advise against drawing conclusions when comparing total annual residential costs.

Furthermore, costs are based on Australian prices, which means we cannot generalise findings to the UK.

In sum, due to the limitations of the costing analysis, findings about the differences in costs should not be used to inform decisions for UK policy.

Considerations

The authors undertook additional analysis using multiple regression to examine whether staffing support and costs were related to individuals’ needs. Individuals’ needs and characteristics were examined using these measures: 1) ICAP service score, the index of participants’ support needs, 2) number of consumers living in the household, and 3) paid hours of night staff support per week, and 4) whether the service was government-provided or privately provided.

Findings show that in both settings paid staff hours and staffing costs were not significantly predicted by individuals’ needs (as measured by the ICAP service score).

In fully-staffed group homes, significant predictors of paid staff hours for individuals were driven by the number of residents and the number of night staff hours.

In semi-independent living arrangements, none of the three other predictor variables were able to significantly explain differences in per person paid staff hours and staff costs.

These findings from the additional analysis indicates that other factors influence the number of paid support hours given to individuals, and this is not related to individuals’ adaptive and challenging behaviour. The implications of the findings are specific to these specific agencies and caution is advised before generalising findings to the UK context.

Conclusions

While it is not possible to come to a conclusion about the relative cost-effectiveness of semi-independent living to fully-staffed group homes, this Australian study finds that individuals in semi-independent living had better outcomes in some areas compared to those living in fully-staffed group homes.

Economics

Review of the costs and outcomes of different types of housing and support in the community

Background and methods

The Guideline Committee wished to make recommendations on different types of housing and support models in the community, but there was very limited research based on the findings of the main guideline systematic review. Since there was limited research focusing specifically on individuals with intellectual disability and behaviour that challenges, additional searches were carried out that included studies that focused on individuals with intellectual disabilities, whether or not the sample included those with behaviour that challenges. The Guideline Committee agreed it was worth doing additional searches in this area of housing and support because recommendations would have a significant impact on individuals' wellbeing and have large resource implications.

The methods of identifying and including studies for review have already been outlined in the beginning of this section (Section 3.1).

Findings

In our additional search of the literature we included a total of 13 studies. In summarising the quality of the research we considered both the newly identified studies in addition to the studies identified through the main guideline search. We found that the research literature lacks robust economic evaluations and a lack of 'gold standard' study designs more generally. None of the included studies were randomised control trials. This means the available evidence can provide an indication of impact, but we cannot be conclusive due to limitations of the study designs. For example, the quality of matched-group study designs varied, but most were low to moderate quality. Another challenge is the lack of a true experimental design where intervention and comparison group services differ by 1 factor – within our research, services in intervention and comparison groups differed by several factors, making it difficult to understand which specific factor caused those changes, not to mention that these study designs are already confounded due to their lack of randomisation or the lack of robust matched-comparison designs.

Conclusions

While these are significant and important limitations, they do not necessarily invalidate the findings, however, they do introduce varying degrees of bias, although the size and direction of that bias is not necessarily clear. For this reason, we care very cautious and cannot conclude with certainty whether some types of housing and support are more or less cost-effective than others.

Economic analysis on respite care: threshold and scenario analyses

Background

Economic modelling was undertaken to assess the potential cost-effectiveness of respite care (for the full report see Appendix C3). We did this analysis because the Guideline Committee made a resource-intensive recommendation for respite care without robust evidence on effectiveness or cost-effectiveness (i.e. RCTs or comparative studies). The difficulty of assessing whether this recommendation on respite care was cost-effective was that the recommendation does not prescribe specific types of respite care. Instead of analysing every possible combination or types of respite care, we use several examples of different respite care intensities, and our analysis is based on the cost of those care examples.

We illustrated the costs of 7 different respite care package intensities for children and 10 different respite care package intensities for adults, ranging from a cost of £5,000 per year to £72,000 per year. The Guideline Committee felt that the range of respite care packages illustrated were satisfactory examples of different intensities of care.

Methods

The method we use to determine when these intensities of respite care can be cost-effective is based on assumptions about cost-offsets and QALY gains to the individual with learning disability and behaviour that challenges, their caregiver(s), and siblings. Cost-offsets occur when using an intervention results in a reduction in the use of public sector services in the short- and medium-term,

In the first step, we undertook a threshold analysis where we calculated the minimum QALY gains that the care packages would have to generate in order to be cost-effective at £20,000 per QALY. For example, if the yearly cost of respite care is £5,000, then it would have to generate 0.25 QALYs for the year in order to be cost-effective. In this step, we assumed that there are no changes in health and social care service use as a result of receiving respite care. Put another way, we assumed that the provision of respite would not cause increases or decrease in service use patterns in health and social care. This first step was important because it served as a benchmark to compare the results of the analysis when we do make assumptions about the impact of respite care on costs and QALYs in the second and third steps.

In the second step, we asked the Guideline Committee to estimate how the absence of respite care would affect QALYs for the caregiver, the individual with learning disability and behaviour that challenges, and any siblings. This step assumed that there were no changes in health, social care, or education costs as a result of receiving respite care. We then undertook scenario analyses about the potential impact that respite care had improving people’s QALYs. Scenario analyses assumed large, moderate, and small improvements in QALYs. From that step, these QALYs that were generated from the Guideline Committee were then compared to the minimum QALYs required from the first step. If the QALYs generated by the Guideline Committee are larger than the results from the threshold analysis, then this indicates that respite care is plausibly cost-effective based on Guideline Committee assumptions.

In the third step, we undertook a separate analysis asking whether respite care could be cost-effective when undertaking a cost-offset analysis. This analysis was prompted based on advice of the Guideline Committee, that respite care could reduce the likelihood of a placement breakdown in the family home, and therefore prevent admission into residential care for the individual with learning disabilities and behaviour that challenges. The Guideline Committee were not sure how other services might be affected and we describe our assumptions regarding service use in the relevant section in the full report. In this step we also conduct sensitivity analyses to check how much the results change (and whether it remains cost-effective) depending on changing assumptions on service use. In this step, we assume there are no changes in QALYs.

Taken together, the several analyses we undertook provide a range of different assumptions which help us to understand whether it is plausible for respite care to be cost-effective in the absence of robust evidence from randomised controlled trials.

Findings

Our analysis demonstrated that respite care, at various intensities, is plausibly a cost-effective and potentially cost-saving option (from a public sector perspective) for both children and adults with learning disabilities and behaviour that challenges.

In the first analysis focusing on changes in QALYs and assuming no change in service use – we found that there are many intensities of respite care that are plausibly cost-effective at £20,000 per QALY, based on Guideline Committee assumptions. In particular:

1. If we assume that the impact of respite care on QALYs results in small improvements, then more costly and intensive respite care packages are not plausibly cost-effective.

2. However, costly and intensive respite care packages are plausibly cost-effective if we assume that respite care delivers moderate or large improvements.

3. More costly and intensive respite care packages are plausibly cost-effective if we assume that QALY gains accrue to more people, i.e. the individual with learning disability with behaviour that challenges and their caregiver(s) and sibling(s).

In the second analysis focusing on changes in costs, we found that respite care is cost-savings to the public sector when measured over a 1-year or 5-year period (discounted at 3.5%). These results are based on the assumption that the baseline probability of a breakdown in the family home is 21.5% for children and 10% for adults with a learning disability and behaviour that challenges. It is also based on the assumption that the effectiveness of respite care in preventing a breakdown is 10% and the average cost of residential care is £149,318/year for children and the average cost of supported living and residential care is £73,040/year for adults (2015/16 prices). The analysis also assumes that the average care package cost for living in the family home is £7,048/year for children and £8,695/year for adults. Respite care was still cost-savings even under sensitivity analyses, where we assumed that the baseline probability of a placement breakdown is 1% for both children and adults, 1% effectiveness of respite care in preventing a breakdown in the family home, and assuming lower-estimate costs (i.e. cheaper) for residential care (i.e. £116,900/year for children and £57,747/year for adults).

Conclusions

The limitations of our analysis are that the data are based on assumptions and are not based on evidence from effectiveness studies.

However, in the absence of data, this analysis is a second-best approach in that it helps identify the key assumptions about costs and QALYs that would be necessary in order for different intensities of respite care to be cost-effective or cost-savings.

We advise extreme caution in drawing conclusions about cost-effectiveness of respite care. This is because we do not know the validity of any assumptions we made. For this reason, we are very cautious about using the results of the analysis when guiding commissioning and provision decisions. We are only sure about the potential range of respite care costs. Beyond that, these scenarios analyses are speculative and their validity cannot be confirmed.

More research is needed to understand the intensities, costs, effectiveness, and cost-effectiveness of respite care that is currently provided to children and adults with intellectual disabilities and behaviour that challenges.

Expert testimony

Community services

The need for expert testimony

We had a lack of evidence direct from people that use services and the services themselves about their experience as to what community-based services help or do not help to achieve and what it is about them that makes this so. We took evidence from an expert witness on best practice for supporting children, young people and adults with learning disabilities in the community.

Testimony

The full testimony from the expert witnesses can be found in Appendix E. A brief summary of their testimony is given below.

The expert witness from Halton Borough Council was a manager of a positive behaviour support service (PBSS). She highlighted in her testimony that the most effective way of delivering a PBSS was in providing a bespoke experience using community-based packages (either with family or own tenancy) with PBSS support and a wider multidisciplinary team.

In terms of what helps to deliver an effective PBSS the expert highlighted the following points. The PBSS should:

- Put the individual in the middle and work around them. Assess their needs, conduct a detailed functional assessment by skilled clinicians, put in place a behavioural support plan and put together a bespoke package of care for that person.
- Work as part of a multidisciplinary team and hold a small caseload at a time (max. of 8 cases).
- Work directly with families/carers/staff to put strategies in place and work across all settings (home, school, short break, outreach, day services etc.).
- Provide out-of-service hours support.

- Work with commissioners to help support people. They can help to highlight barriers and reflect on things from which lessons can be learned (such as risk management, negative staff culture, high turnover of support staff etc.).
- Put in place robust maintenance and discharge procedures to prevent ‘procedural drift’.

In terms of what gets in the way of delivering an effective PBSS the expert suggested these were the main barriers:

- Parent burn-out or mental health issues.
- Overzealous risk assessments, which significantly reduce opportunities for individuals.
- An established negative staff culture
- Recruitment of support staff. The expert said that frequently support agencies do not maintain their staff and this appears be related to burn-out, pay rates etc.
- General culture where a lot of professionals still feel that residential placements are ‘safer’ for people who engage in behaviour that challenges services, rather than focusing on community living.

The expert also suggested that these components would help deliver an effective PBSS:

- Practitioners who have the skills in creating good quality behavioural support plans and who give the right support.
- Staff that understand people’s behavioural needs.
- Teams carrying out very detailed functional assessments.
- Specialist teams being effectively linked into the wider support to the person.
- Working across all settings that the person is linked to.
- Having very small caseloads at 1 time, for example 8 per behavioural analyst.
- Providing out-of-hours support.

Inpatient services

The need for expert testimony

We did not find any rigorous research evidence meeting our criteria to evaluate the effectiveness and cost-effectiveness of different types of inpatient services. To help fill this evidence gap we wanted to find out more about the use of inpatient services for our population. We also asked the other expert witnesses if they had any specific experiences of the use of inpatient services that they would like to share with the Guideline Committee. Where relevant points were made about inpatient services from the other expert witnesses they are included below.

Testimony

The full testimony from the expert witnesses can be found in Appendix E. A brief summary of their testimony is given here.

Expert testimony was provided by a consultant forensic adolescent learning disability psychiatrist. Her testimony confirmed that the population served by inpatient services falls into 3 groupings: those with behaviour that challenges; forensic patients; and mixed (or unknown). She also said that people are presenting with complicated situations and that children from looked-after care groups are more likely to be admitted to inpatient services. Her testimony also highlighted the main reason or purpose of admission as:

- Risk both to self and/or others (occasionally property).
- Safeguarding: either to an individual or due to an individual’s behaviour.
- Intensity of support/intervention/assessment.
- Legal framework: alternative to custody; legal framework for treatment or intervention.
- Engagement: for individuals or families who find it difficult to engage with services or who are difficult to engage, inpatient admission may be the only way to either start that engagement process or engage with a young person or their family in any way.

When it comes to what helps inpatient services to work best, the expert witness suggested that services work best when the ‘person’ is at the centre and expertise is leveraged around that person. Solutions are likely to be informal rather than structural. She also emphasised the importance of making reasonable adjustments for people with learning disabilities in inpatient settings.

When it comes to what helps services work better together, the expert witness suggested that legal frameworks, finances, transitional arrangements and pathways, professional and multiprofessional networks are all factors that help the interface between services work well. She also suggested that step-down services might be more helpful for adults, but not as helpful for adolescents because more change causes a lot of anxiety for the young person.

In terms of the main things that get in the way of inpatient services working effectively, the expert witness highlighted that there is some confusion over the concept of secure inpatient services as opposed to forensic inpatient services and physically robust inpatient services with a high level of specialist staffing. She also suggested that is inappropriate for people with a learning disability to be on mixed sex mental health units.

Other expert testimony

The expert witness who is a manager of a positive behaviour support service highlighted in her testimony that from her experience it was very difficult for any inpatient service to be effective in treatment plans unless these plans are for a short period of time and very treatment focused. See expert testimony in section 3.1 above for further detail. The same point was also made by 2 of the expert witnesses from Devon that gave testimony on best practice in supporting a person with learning disabilities in the community. See expert testimony in section 3.3 for further detail. The expert witnesses from Devon also highlighted the issue of inpatient services ability to engage with and work in partnership with the person and the person’s family and any community supports that person may have.

Evidence statements

For details of how the evidence is graded and on writing evidence statements, see Developing NICE guidelines: the manual.

SP1	**Community based (residential) – semi-independent living vs. fully-staffed settings** There was weak evidence from 1 moderate (+) quality non-randomised, matched-group study from the UK with a small sample size (n=70) that compared fully-staffed group homes to semi-independent living (Felce et al. 2008 +). The study found semi-independent living has mixed beneficial effects for adults with low to medium support needs when compared to fully staffed group homes. On the one hand, the study found that semi-independent living offered greater opportunities to exercise choice and control and people living in semi-independent homes were at no greater risk of victimisation or accidents. On the other hand, the study found that semi-independent living can place people at greater risk of poorer physical health due to lifestyle choices and financial difficulties.
SP2	**Congregate vs. non-congregate settings** There was moderate evidence from 2 UK quasi-experimental studies (Golding et al. 2005 +; Robertson et al. 2004 +) which compared quality of life and behaviour outcomes for people with mild to moderate intellectual disabilities and severe behaviour that challenges moving into community-based settings. Golding et al. (2005 +) (n=12) found that congregate community-based homes were more beneficial compared to the hospital residential unit; Robertson et al. (2004 +) (n=50) found that non-congregate community-based homes are more beneficial than congregate homes.
SP3	**In-area vs. out-of-area placements** There was weak evidence from 1 low quality (−) non-randomised, matched-group study from the UK with a small sample size (n=76) that compared in-area to out-of-area placements (Perry et al. 2013 −). It focused on adults with learning disabilities and challenging behaviour with a mixed range of needs. There were few differences found between the groups on quality of life measures. Exceptions were that people who were placed in-area had had more activities in the last month, had more visits from friends, but a higher proportion were inactive and less likely to have moderate/vigorous activity in the last month.
SP8	**Effectiveness of community forensic services** There was a small amount of evidence from 2 studies, both of which were retrospective case note reviews of low quality, which found that specialist community forensic services (CFT) were more likely to provide access to appropriate treatment services compared to general community services and secure services for people with a learning disability and forensic needs. The first of these 2 studies, Lindsay et al. (2013 −) (n=197), found that community forensic services and inpatient services provided appropriate treatment for 89% of referrals for violence and sexual offences, compared to only 9% of referrals receiving appropriate treatment by general community teams and 27% for secure services. The Browning et al. (2016 −) study (n=70) found that since referral to the community forensic team, over 2-thirds of all service users had received input from speech and language therapy, occupational therapy and psychology. A total of 30% of service users had received offence-specific interventions such as adapted sexual offender treatment programmes, fire-setter treatment programmes (FSTPs), anger management and thinking skills. The CFT are trained in and able to provide a wide range of offence-related interventions. Since referral to the CFT there was a reduction in people living in out-of-area secure units and an increase of people living in the community under their care.

SP4	**Effectiveness of types of inpatient services** The review did not identify any well designed studies that could identify the effectiveness of different types of inpatient services.
EcSP1	**Semi-independent living** There was evidence from 1 moderate (+) quality non-randomised, matched-group study from the UK with a small sample size (n=70) on the relative cost-effectiveness of semi-independent living compared to fully staffed group homes (Felce et al. 2008 +). The evaluation focuses on individuals with low to medium support needs. The time horizon of the analysis was 3 months. The perspective of the analysis is that of the NHS and personal social services. Based on the limitations of the study and weaknesses in economic methods, it is not possible to make firm conclusions about cost-effectiveness.
EcSP2	**Congregate to non-congregate settings** There was 1 non-randomised, matched-group study from the UK with a small sample size (n=50) that compared congregate to non-congregate settings (Robertson et al. 2004 +). The evaluation focused on individuals with severe learning disabilities and challenging behaviour. The time horizon of the analysis was 1 year for costs and 10 months for outcomes. The perspective of the analysis was that of the NHS and personal social services. Based on the limitations of the study and weaknesses in economic methods, it is not possible to determine whether congregate or non-congregate placements are relatively more cost-effective.
EcSP3	**In-area vs. out-of-area placements** There was evidence from 1 low quality (−) non-randomised, matched-group study from the UK with a small sample size (n=76) on the relative cost-effectiveness of in-area vs. out-of-area placements (Perry et al. 2013 −). It focused on adults with learning disabilities and challenging behaviour with a mixed range of needs. The perspective of the analysis was that of the NHS and personal social services and also considered the cost of travel for families. Based on the limitations of the study and weaknesses in economic methods, it is not possible to determine whether in-area or out-of-area placements are relatively more cost-effective.
EcU1	**Housing and support options** There is limited evidence from 1 low quality review (n=not specified) on the costs and cost-effectiveness of different housing and support models for people with learning disabilities (Harflett et al. 2017 −). The review found that the evidence on costs and cost-effectiveness of different housing and support models is unclear based on current available research.
SP5	**Community-based services – respite services and impact on family functioning** There was qualitative evidence from 2 moderate quality studies (Brown et al. 2011 +, n= families of 23 children; Slevin and Sines 2005 ++, n=22 community nurses) and 1 high quality study (McConkey et al. 2013 ++, n= 123 families) (all UK studies) that the availability of respite care or other part-time residential options can prevent the deterioration of the families ability to cope over time, and may prevent full-time residential placements and hospital admissions.
SP6	**Community-based (residential) – semi-independent living**

	There was weak evidence from 1 low quality US qualitative study (Pearson 2012 −) (n=10) that fully independent living was preferred to semi-independent living apartments for adolescents with developmental disorders and high risk behaviour such as aggression, inappropriate sexual or offending behaviour. Participants in this study had mixed feeling about the semi-independent living arrangements and felt they had little choice or control in their lives and the living arrangements were not like real life.
SP7	**Inpatient services** There is weak evidence from a low quality qualitative UK study (Pratt et al. 2012 −) (n=20 staff and 4 families) of the acceptability and feasibility of a pre-planning checklist and named nurse coordinator for children with autistic spectrum disorders and behaviour that challenges who were due to be admitted to hospital to prevent distress and behaviour that challenges. The pre-planning checklist was developed to understand the specific needs of the children, such as any sensitivities, routines and dislikes that may trigger behaviour that challenges if unknown to staff on admission. Based on the results, staff were able to pre-plan strategies to overcome barriers and to care for the children's particular needs.
SP9	**Views of community forensic services** There is a small amount of evidence from 1 moderate quality qualitative study (Davis et al. 2015 +) (n=10) about what people with learning disabilities and forensic needs think about living in the community, subject to a forensic community rehabilitation order. Most people in this study liked that they had more freedom and choice in their daily lives, but also felt frustrated at the lack of control they had over their situation, for example, lack of control in relation to their care plan. Participants felt shame with needing help to care for themselves and at having someone with them at all times in public. Some participants missed the close living quarters in hospital and sense of community this created and described having very limited social networks in the community and staff becoming like friends which meant it was difficult for them to consider moving on and not having staff with them all the time.
HPBS01	**Features of a Positive Behavioural Support Service** This evidence statement is based on expert witness testimony from Halton Borough Council, which provides a Positive Behavioural Support Service. The testimony stated aspects that make PBSS a service successful. This included: • Supported intervention in which PBSS staff work directly with families/carers/staff to put strategies in place • If additional family support needs are identified, working with social care to identify a different support package for the family.
HPBS02	**Support in the community** This evidence statement is based on expert witness testimony from Halton Borough Council, which provides a Positive Behavioural Support Service. The expert witness highlighted the following features of the service as important to its success:

	- workers hold small caseloads to allow an intensive support package. Some service users are visited daily. - The work is intensive to give optimum success and reduce the likelihood of referral back to the service. In practice, the number of individuals referred back to the service is very small.
HPBS03	**Out of hours support** This evidence statement is based on expert witness testimony from Halton Borough Council, which provides a Positive Behavioural Support Service. The expert witness described the out of hours support provided by the service, which they thought was an important element of the success of the service. Staff in the PBSS provide direct support to families early in the morning or over the weekend if that is what is required. A recent review showed challenging behaviour was most likely to occur in the middle of the night, so this is when the allocated behaviour analyst conducts their observations for assessment.
HPBS04	**Robust maintenance and discharge procedures** This evidence statement is based on expert witness testimony from Halton Borough Council, which provides a Positive Behavioural Support Service. The expert witness thought that an important feature of the service was ensuring that specific strategies for supporting a person continue to be implemented after they have left the care of the intensive support service. This involved working with the person’s family and day to day carers.
HPBS 05	**Working with families** This evidence statement is based on expert witness testimony from Halton Borough Council, which provides a Positive Behavioural Support Service. In the expert witness testimony example, the Positive Behavioural Service (PBSS) tends to work with those individuals with the most complex needs who require a full functional assessment, PCIP and supported intervention. The other teams will refer to PBSS when they feel an individual requires specialist input. This has advantages and disadvantages. The PBSS is not resourced to treat everyone locally who engages in challenging behaviour and therefore it is appropriate for other services to support. However, on occasion individuals end up going through all services and still coming to PBSS. At this point families/staff can be quite disheartened and less willing to engage. The testimony acknowledged some of the situations that make it more difficult to successfully support an individual including parent burn out or mental health issues.
HPBS06	**What works: Staff skills and experience** **HPBS06 What works: Staff skills and experience** This evidence statement is based on expert witness testimony from Halton Borough Council, which provides a Positive Behavioural Support Service. The expert witness testimony highlighted the importance of staff skills within a Positive Behaviour Support Service including:

	- providing specific training opportunities for example Active Support - working to change the culture amongst staff groups who are focused on the individuals 'needing to know their behaviour is wrong' and over-use of sanctions. The testimony also highlighted difficulties caused by high staff turnover amongst support staff. This can mean that the PBSS will train staff to implement an intervention, many of whom will then leave.
IP01	**Making the right use of inpatient services** This evidence statement is based on expert witness testimony from a clinical forensic and learning disability psychiatrist with experience of working with children and young people with learning disabilities and behaviour that challenges. The witness stated that in their experience that if there are good community services, including good joint working between health, social care and education, a lot of inpatient admissions may be circumvented. The witness also advocated having a meeting prior to admission to ensure that all options within the community have been fully considered. When an inpatient admission is required, the focus should be reducing the length of stay. The expert witness thought that much of what can be delivered in an inpatient setting could actually can be delivered in the community.
IP02	**Legal frameworks** This evidence statement is based on expert witness testimony from a clinical forensic and learning disability psychiatrist with experience of working with children and young people with learning disabilities and behaviour that challenges. The expert witness' view was that legal frameworks are currently insufficient for smooth transition particularly in adult services, for example deprivation of liberty. There are some good things, for instance in developing personal relationships. Knowing other practitioners in a neighbouring authority helps to discuss issues directly.
IP03	**Commissioning** This evidence statement is based on expert witness testimony from a clinical forensic and learning disability psychiatrist with experience of working with children and young people with learning disabilities and behaviour that challenges. The expert witness' view was that, given the complex and specialist needs of people with learning disabilities and behaviour that challenges, it may be appropriate to have a nationally commissioned specialist assessment service, which could work with and advise local services.

EcH1	**Congregate vs. non-congregate residential settings** **Outcomes for residents** There is evidence from 2 studies of low to moderate quality (Mansell and Beadle-Brown 2004 −; Robertson et al. 2004 +), which show that, on balance, congregate settings result in inferior outcomes for adults with intellectual disabilities and challenging behaviour.

	The review by (Mansell and Beadle-Brown 2004 −) identified 3 non-randomised comparative UK studies which found that individuals with challenging behaviour do worse in congregate settings than they do in non-congregate (mixed) settings, where congregateness is measured as settings having between 50% to 75% of individuals with challenging behaviour. There is evidence from 1 moderate quality non-randomised matched comparison UK study (Robertson et al. 2004 +) (n=50) that congregate settings had worse outcomes in 2 outcome domains: methods for the treatment and control of challenging behaviour and quality of life (although for many measures there were no differences). There were no differences between settings for risks and injuries. Non-congregate settings were inferior in some of the measures of working practices, but these process-oriented outcomes did not translate into superior outcomes as described above in terms of methods of treatment and control of challenging behaviour and quality of life. Moreover, whilst congregate settings had higher staffing ratios, this did not lend itself to better outcomes. Results are limited due to small sample size and use of older data. Caution is advised before generalising results.
EcH2	**Congregate vs. non-congregate residential settings** **Outcomes for co-residents** There is evidence from 1 low quality review (Mansell and Beadle-Brown 2004−), which identified 1 non-randomised comparative UK study that found that being a co-resident of individuals with challenging behaviour in congregate settings did not affect 15/15 of co-residents' service standards. However, service standards are not the same as quality of life or other individual-focused outcomes. Further research is needed to understand the effects of congregate settings on co-residents' quality of life. In this study, congregateness was defined as 50% or more of the setting containing individuals with challenging behaviour. Results are limited due to small sample size and use of older data. Caution is advised before generalising results. With regards to risks and injuries received from co-tenants, there is limited evidence from 1 moderate quality non-randomised matched comparison UK study (Robertson et al. 2004 +) (n=50) that there were worse outcomes in congregate settings. At one of the two time points in a 10-month period, a significantly higher number of people in congregate settings (44%), compared to non-congregate settings (15%) received a minor injury from their co-tenants (p<0.0001). With regard to the impact on co-tenants' number and variety of community activities undertaken in the past 4 weeks, there is limited evidence from 1 moderate quality non-randomised matched comparison UK study (Robertson et al. 2004 +) that found better results for non-congregate settings at both time 1 (p≤0.05) and time 2 (p<0.05). Co-residents in non-congregate settings had a greater number of community activities (T1= 23 activities, T2= 17.6) compared to those in congregate settings (T1=15.7, T2=10.1) although the variety of activities was the same across congregate and non-congregate settings.
EcH3	**Congregate vs. non-congregate residential settings** **Costs** There is evidence from 1 non-randomised matched comparison UK study (n=50) (Robertson et al. 2004 +), which found that the total annual cost of

	non-congregate settings was significantly lower (£12,011 less per year) than congregate settings. Lower costs were mainly due to lower staffing levels. However, due to limitations in economic methods, it is not clear whether differences in total costs are due to differences in prices or differences in resources inputs. Results are limited due to small sample size and use of older data. Caution is advised before generalising results.
EcH4	**Characteristics and service factors relating to out-of-area placements and access to services** **Population: adults with intellectual disabilities** There is consistent evidence from 1 review and 3 studies of low to moderate quality relating to the individual characteristics and service characteristics leading to an out-of-area placement among adults with intellectual disabilities. One low quality review (Emerson and Robertson et al. 2008 −; (n=not specified) and one moderate quality local survey (Joyce et al. 2001 +) (n=448) identify the reasons for out-of-area placements to include: • a lack of suitable local services • placement breakdown, or • a lack of satisfaction with local services. There is evidence from two moderate quality local surveys (Joyce et al. 2001 +; Hassiotis et al. 2008 +, n=205) that younger people were more likely to be placed out-of-area and that reasons for out-of-area placements include a lack of organisation and planning for young people transitioning into adult services. One low quality review (Emerson and Robertson 2008 −) finds that adults with intellectual disabilities were more likely to be in out-of-area placements if they had: • challenging behaviour • autism • mental health needs • complex health needs, and • forensic needs. This is supported by 1 low quality cross-sectional study of 1 NHS Trust in Wales (Allen et al. 2007 −), of (n= 1458 service users, where data was collected for 901 people) that found that individuals with intellectual disabilities were more likely to be placed out-of-area if they had: • more complex needs • had a history of formal detention under the mental health act • presence of mental health problems • formal diagnosis of autism • higher adaptive behaviour • behaviour leading to physical injury to the participant themselves (repeated incidents and usual consequence), and • exclusion from service settings.
EcH5	**Costs of in-area vs. out-of-area placements** **Population: Adults with intellectual disabilities**

	There is mixed evidence from 1 low quality review focusing on adults with intellectual disabilities regarding the costs of in-area vs. out-of-area placements. There are no adequate study designs that can tell us whether in-area vs. out-of-area placement is more or less cost-effective. 1 low quality review (Emerson and Robertson 2008 −) finds that adults with learning disabilities in out-of-area placements have slightly higher costs than in-area placements, but this may be attributed to individuals' in out-of-area placements having greater needs. This would be consistent with findings that predictors of out-of-area placements include challenging behaviour, autism, mental health, complex health needs, and forensic needs.
EcH6	**Access to services, comparing in-area vs. out-of-area placements** **Population: Adults with intellectual disabilities** There is consistent evidence from 2 studies of low quality focusing on adults with intellectual disabilities studying the quality of access to services among those in out-of-area and in-area placements. Findings show that people in out-of-area placements do not necessarily receive superior services. There is evidence from 1 low quality cross-sectional study of individuals served by one NHS Trust in Wales (Allen et al. 2007 −) (n= 1458 service users, data were available for 901 people) which found that people in out-of-area placements are not receiving appropriate levels of access to professional support and organisations' working practices were not as high as would be expected considering that they were viewed as 'specialist' services and were expected to provide specialist services. There is evidence from 1 low quality review (Emerson and Robertson 2008 −) that in some areas, individuals in out-of-area placements accessed local services rather than being given specialist care through the providing agency. Such findings indicate an inappropriate use of resources; as such investments could have been invested in the person's home area
EcH7	**Characteristics and service factors relating to out-of-area placements and access to services** **Population: subgroup of adults with intellectual disabilities with the highest-cost care packages** There is some consistent evidence from 3 surveys of low to moderate quality focusing on a subgroup of adults with intellectual disabilities that have the highest-cost care packages regarding the characteristics and service factors that predict out-of-area placements. There is 1 moderate quality population survey of 3 London boroughs (Joyce et al. 2001 +) (n=448) which found that individuals with intellectual disabilities were more likely to be placed out-of-area if they were: • male • black • aggressive or had damaging behaviour • living in a particular borough. There were similar findings from 1 low quality 2009/10 survey of n=70 adults in 14 local authorities in South East England (McGill and Poynter 2011 −) which found that predictors of out-of-area placements were:

	- male gender - living in residential care, and - not living in supported living accommodation. 1 recent, moderate quality follow-up survey of adults in 14 local authorities in South East region of England (n=105) (Deveau et al. 2016 +) found that individuals in out-of-area placements were more likely to: - have a mental health diagnosis - display offending behaviour - be in hospital, or - be in a secure or medium secure unit.
EcH8	**Costs of in-area vs. out-of-area placements** **Population: subgroup of adults with intellectual disabilities and highest-cost care packages** There is mixed evidence from 3 studies of low to moderate quality focusing on a subgroup of adults with intellectual disabilities that have the highest-cost care packages regarding the costs of in-area vs. out-of-area placements. One moderate quality survey of 14 local authorities' top five highest-cost care packages for adults with intellectual disabilities in South East of England (Deveau et al. 2016 +) found that the costs for individuals with intellectual disabilities (n=105) in out-of-area placements were no different than in-area placements, but individuals in out-of-area placements were more likely to have a mental health diagnosis, offending behaviour, be in hospital, or be in a secure or medium secure unit. This was a follow-up study of a low quality survey conducted in 2009/10 based on a sample of n=70 adults with intellectual disabilities (McGill and Poynter 2011 −) which also found no differences in costs between those in out-of-area vs. in-area placements. One moderate quality survey of 5 London boroughs' subgroup of n=205 adults with intellectual disabilities and have the highest-cost care packages (£70k+/year) (Hassiotis et al. 2008 +) found that the mean and median annual costs of out-of-area placements cost slightly more than in-area placements (however statistical significance is not provided); however the cost estimates limited due to difficulties in calculating costs using standard methodology across the boroughs.
EcH9	**Access to services, comparing in-area vs. out-of-area placements.** **Population: subgroup of adults with intellectual disabilities with the highest-cost care packages** There is mixed evidence from 2 studies of moderate quality that people in out-of-area placements do not necessarily get superior services. 1 moderate quality survey of n=80 service providers from 5 London boroughs from 2005/06 focusing on individuals with learning disabilities with the highest-cost care packages (£70k+/year) (Barron et al. 2011 +). The study results are based on data from n=54 individuals with intellectual disabilities and who had the highest cost care packages. The analysis found that access to psychiatrists was high but that access to all other professionals was low, including psychologists, speech and language therapists, nurses, and occupational therapists. 1 moderate quality survey of 5 London boroughs (Hassiotis et al. 2008 +) among a subgroup of individuals with intellectual disabilities and challenging

	behaviour with the highest-cost care packages (n=205) (£70k+ per year) found that service standards seem to be higher for out-of-area placements than in-area placements, and lower scores were clustered around lower-cost placements (which were mostly in in-area placements). However findings are limited as they are only available for half of the sample (n=102/205).
EcH10	**Outcomes and costs of in-area vs. out-of-area placements.** There is limited evidence from 1 low quality non-randomised matched comparison study (Perry et al. 2013 −) (n=76), which found that people in out-of-area placements did worse in 2 areas of quality of life but were not different in all other areas of quality of life. This same study found that people in out-of-area placements did worse in 2 areas of health, but for all other areas of health there were no differences. There were also no differences between in-area or out-of-area placements in relation to safety and lifestyle satisfaction. This same study found that in-area placements had higher total costs, due to higher levels of staffing, administration and overheads, higher cost of daytime activities and hospital services, even though groups were similarly matched on levels of adaptive behaviour and mental health problems. These differences in costs were still significant even after adjusting for differences in settings' level of challenging behaviour ($p<0.001$). However, it is not clear how much of these differences are due limitations in economic methodology. It is unclear how much of the differences in costs are due to differences in prices or differences in resource use, as prices were not based on national unit costs, but rather, facility-specific charges. For this reason, conclusions on costs are not clear. This study also found that the cost of travel for families visiting out-of-area placements is 4 times higher than those families visiting in-area placements. The conclusions about the impact on costs to families are robust.
EcH11	**Referral and response to abuse.** **Population: adults with intellectual disabilities who have been referred to local authority on suspicions of abuse** There is limited evidence from 1 good quality prospective cohort study (n=1926) (Beadle-Brown et al. 2010 ++), which compares referrals and response data for abuse among individuals living in in-area (n=1224) vs. out-of-area (n=339) from 1998 to 2005 from 2 local authorities in South East of England. The study is not designed to answer questions about whether individuals are more or less likely of being abused. This study is only designed to answer whether, if referred, whether patterns of abuse are similar or different among those living in-area vs. out-of-area. The study finds that if referred to local authority, individuals in out-of-area placements, compared to those living in in-area placements, had greater rates of multiple types of abuse, physical abuse, psychological abuse, neglect, institutional and discriminatory abuse.
EcH12	**Cluster vs. dispersed housing.** **Population: adults with intellectual disabilities** There is evidence from 1 low quality review (Mansell and Beadle-Brown 2009 −) (n=19 studies) regarding the effects of cluster vs. dispersed housing for adults with intellectual disabilities. This review finds that across many outcome measures, individuals in various types of dispersed housing arrangements have better outcomes than individuals in clustered campus or cluster residential housing (individuals in cluster housing either did worse or no different to cluster housing). These outcomes include: social inclusion,

	interpersonal relations, material and emotional wellbeing, self-determination, personal development and rights, home-likeness, environmental quality and number of people sharing the home, staff ratio and staff contact and assistance. The exception is village communities, where individuals had similar or were no different to dispersed housing. These outcomes include: interpersonal relations, physical wellbeing, medication, safety, certain types of health checks, social climate and working practices. The only area in which individuals in campus residential housing did better than individuals in dispersed housing was in receiving health checks. This indicates that individuals living in dispersed housing arrangements may need additional support to ensure they receive timely and all relevant health checks.
EcH13	**Cluster vs. dispersed housing: Costs** **Population: adults with intellectual disabilities** There is limited evidence on costs in relation to cluster vs. dispersed housing among adults with intellectual disabilities. One low quality review (Mansell and Beadle-Brown 2009 −) (n=19 studies) finds that cluster housing has lower costs than dispersed housing, and this is due to lower staffing levels. However, the authors conclude that while cluster housing was cheaper, this did not result in good outcomes for individuals, in fact outcomes were worse. The only exception to this is village community, which performed similar to or in some cases better than dispersed housing and costs were lower than dispersed housing. However, once levels of staffing are taken into account, the costs of village community and dispersed housing are similar.
EcH14	**Environmental and service factors influencing outcomes and costs** **institutional vs. community settings: outcomes** **Population: adults with intellectual disabilities** There is consistent evidence from 2 reviews of low to moderate quality that find the balance of evidence in favour of community settings compared to institutional settings for adults with intellectual disabilities (Felce 2016 −; Kozma et al. 2009 +, n=68 studies). This includes better outcomes for: • community participation, • family contact, • self-determination and choice, • quality of life, • adaptive behaviour, • user and family views and satisfaction, • social networks and friendships (improvements noted in more recent reviews, whereas studies from older reviews found no differences). The impact on challenging behaviour was mixed, although most studies showed no differences. The impact on health and mortality is not clear.
EcH15	**Environmental and service factors influencing outcomes and costs** **Institutional vs. community settings: costs** **Population: adults with intellectual disabilities**

	There is equivocal evidence from 1 low quality review (Felce 2016 −) regarding the difference in costs between institutional and community settings among adults with intellectual disabilities. Among UK studies, community housing was slightly more expensive than institutional settings but studies were limited by lack of comprehensiveness of costs. Studies from the 1990s conducted more comprehensive cost analyses and still found costs of community housing to be higher. However, there is evidence that the costs of community housing may decline in the long-term, as was found in 1 longitudinal study published in 2006. The cost of community-based housing was higher by £162/week in the first year but progressively declined to £29/week in the twelfth year. In conclusion, findings on costs are not entirely clear due to limitations in economic methods and the lack of comprehensiveness cost analysis.
EcH16	**Environmental and service factors influencing outcomes and costs** **Impact of setting size: outcomes** Population: adults with intellectual disabilities There is consistent evidence from 3 reviews of mixed quality, which conclude that setting size has an impact on outcomes: Felce (2016 −), Kozma et al. (2009 +) and Bigby and Beadle-Brown (2016 +). One moderate quality review (n=not specified) concludes that small ordinary housing that is home-like, and dispersed within the community has better outcomes for individuals with learning disability (Bigby and Beadle-Brown 2016 +). One low quality review (n=not specified) lends support and concludes that setting size has an indirect and positive effect on outcomes when housing is home-like, physically integrated into the community, and has a standard architectural design (Felce 2016 −). One moderate quality review (n=68 studies) found similar results (Kozma et al. 2009 +). Some studies found that individuals had more friends if they were living in small settings and with low staff turnover, other studies found individuals had greater choice and opportunity for self-determination when individuals lived in smaller settings that were more individualised, compared to individuals in larger, congregate settings, and other studies found that small residence size and stimulation of the home environment had a positive effect on individuals' level of adaptive behaviour.
EcH17	**Environmental and service factors influencing outcomes and costs** **Impact of setting size: Costs** **Population: adults with intellectual disabilities** There is evidence from 1 low quality review (Felce 2016 −) regarding the impact of setting size on costs among adults with intellectual disabilities. The review found that: • Within community housing models, there are economies of scale up to a residence size of 6 and beyond that, there are no additional economies of scale. • Within residences with 6 or fewer placements, smaller settings were more costly, but the effect on costs was small, and other factors had a greater contribution in explaining differences in costs. One study in the review found economies of scale among individuals with lower levels of ability but no economies of scale when individuals had higher levels of ability. It is not reported why this is the case.

	In another study, there were economies of scale when staffing levels were fixed but there were no economies of scale when staffing levels were variable and individualised to level of need.
EcH18	**Environmental and service-related factors and effects on individual outcomes.** **Population: adults with intellectual disabilities** There was 1 moderate quality review (Bigby and Beadle-Brown 2016 +) which reviewed the evidence regarding the impact of environmental and service-related factors affecting individual outcomes. The review found that outcomes for individuals were better when: • Staffing is closely matched to individual's level of need, staff are trained in effective working methods, for example, 'active support', and staff are enabling and empowering people to do things themselves. • Front-line managers practice leadership in the development and maintenance of active support – as this is likely to have a positive indirect impact on individuals' outcomes via staff working practices. • Organisations have their values translated into clear expectations of staff. This is likely to have a positive impact on individuals' outcomes. • Settings are less restrictive – as individuals had a lower probability of inactivity, however, this led to an increase in the probability for smoking, poor diet, and obesity. • Individuals live closer to their families – as increased distance from family was associated with fewer contacts, and this was more likely among individuals who had lower levels of ability and/or if they and their families were older. • Residents are compatible – leading to a lower likeliness of loneliness, which was more likely in larger residential settings. • Accommodation is home-like and homes are physically integrated into the community. This led to better outcomes, including greater choice and opportunity for self-determination. There was not enough research in the following areas: • External factors such as: standards, inspections, family influence and wages are under-researched. Inspector ratings focus on management, staff training, systems and processes, but do not monitor other quality of life outcomes for service users. • Impact of neighbourhood characteristics on outcomes. • Impact of organisational characteristics on outcomes. • Staff characteristics.
EcH19	**Semi-independent vs. fully-staffed group homes: outcomes** **Population: adults with intellectual disabilities** There is evidence from 2 non-randomised matched comparison studies of low to moderate quality, 1 from Australia (n=54) (Stancliffe and Keane 2000 −) and 1 from the UK (n=55) (Felce et al. 2008 +), and 2 reviews of low to moderate quality (Felce 2016 − ; Kozma et al. 2009 +) relating to the outcomes of semi-independent living arrangements for adults with intellectual disabilities and/or challenging behaviour. For more detail about the study samples' level of intellectual disability and level of challenging behaviour, refer to the narrative summaries.

	Evidence from 1 low quality Australian study (n=54) (Stancliffe and Keane 2000 −) and 1 moderate quality UK study (n=55) (Felce et al. 2008 +) finds that adults in semi-independent living arrangements, who have been assessed as having low support needs, compared to similar individuals living in fully-staffed ‘traditional’ settings or group homes (where both settings had between 1–3 or 4–6 residents) had better outcomes for: • choice and independence, • greater feelings of empowerment and independence, • participation in domestic tasks. There were mixed results for household management and health. One low quality Australian study (n=54) (Stancliffe and Keane 2000 −) found no differences and 1 moderate quality UK study (n=55) (Felce et al. 2008 +) found that in some areas, those with semi-independent living arrangements did either worse or no different to those in fully staffed group homes. In relation to community participation and integration, the balance of evidence is in favour of semi-independent living. This is based on the findings of 1 moderate quality review (Kozma et al. 2009 +), which found better outcomes from 3 studies, and this was supported by 1 low quality Australian study (n=54) (Stancliffe and Keane 2000 −) which also found better outcomes. One moderate quality UK study (n=55) found no differences (Felce et al. 2008 +). There were no differences in the following outcomes based on the findings of 1 moderate quality UK study (n=55) (Felce et al. 2008 +) and 1 low quality Australian study (n=54) (Stancliffe and Keane 2000 −): • Safety (Stancliffe and Keane 2000 −; Felce et al. 2008 +). • Home-likeness (Felce et al. 2008 +) • Risk (Felce et al. 2008 +) • Loneliness (Felce et al. 2008 +) • Living companion turn-over (Stancliffe and Keane 2000 −) • Personal care (Stancliffe and Keane 2000 −) • Domestic management (Stancliffe and Keane 2000 −).
EcH20	**Semi-independent vs. fully-staffed group homes: costs** **Population: adults with intellectual disabilities** There is evidence from 2 non-randomised matched comparison studies of low to moderate quality, 1 from Australia (n=54) (Stancliffe and Keane 2000 −) and 1 from the UK (n=55) (Felce et al. 2008 +), and 1 low quality review (Felce 2016 −) relating to the costs of semi-independent living arrangements for adults with intellectual disabilities and/or challenging behaviour. For more detail about the study samples’ level of intellectual disability and level of challenging behaviour, refer to the narrative summaries for more detail. 1 moderate quality UK study (n=55) (Felce et al. 2008 +) found that semi-independent living had lower total costs than fully-staffed group homes. The cost perspective was that of the NHS and personal social services. Findings on non-accommodation costs are robust but caution is advised in drawing conclusions about differences in accommodation costs. It is unclear how much of the lower accommodation costs are due to lower prices or lower use of resources. 1 low quality Australian study (n=54) (Stancliffe and Keane 2000 −) took the cost perspective of the service provider. Findings are not applicable to the UK context due to differences in institutional context and unit costs. With

	those limitations in mind, the Australian study found that total staff support costs were lower for semi-independent living, due to lower staffing hours per person. 1 low quality review (Felce 2016 −) identified 2 different studies showing that semi-independent living arrangements had costs that were no different to 'traditional' support (citing 1 US study, Howe, Horner, and Newton 1998) or fully-staffed group homes with 1-3 residents or 4-6 residents (citing 1 UK study, Emerson et al 2001).
EcH22	**Shared Lives** **Population: adults with intellectual disabilities** There is evidence from 1 low quality costing study (Curtis 2011 −) that, as of 2009, a majority of Shared Lives service users were individuals with intellectual disabilities (88%).
EcH23	**Shared Lives: Outcomes and costs** **Population: Adults with intellectual disabilities** There is evidence from 1 low quality costing study (Curtis 2011 −) (n=not specified) and 1 low quality report (NAAPS 2010 −) (n=not specified) that Shared Lives can provide better outcomes compared to residential care homes, as measured by CQC inspection ratings and CQC's collection of feedback from service users. However findings refer to individuals with learning disabilities; it is not clear whether individuals with challenging behaviour are included. A limitation of the findings is that the evidence is based on a descriptive evaluation and not based on systematic and formalised study designs. While findings from CQC inspections are positive and promising, further research is needed to increase confidence in findings. Evidence from 1 low quality costing study (Curtis 2011 −) (n=not specified) and 1 low quality report (NAAPS 2010 −) (n=not specified) finds that, for adults with intellectual disabilities, Shared Lives can provide cost savings compared to residential services and semi-independent living arrangements. The estimated long-term average cost of Shared Lives scheme for an adult with learning disability and who would otherwise live in residential care is £419 per week and it is estimated to be £293/week for an adult who might otherwise live in semi-independent living arrangements (2009 prices). However, those costs may be underestimates, but by how much is unclear - not all of the costs associated with Shared Lives service were included in those estimates (does not include insurance, office equipment and supplies, operational costs and travel). Evidence from 1 low quality report (NAAPS 2010 −) (n=not specified) finds that, in 2009, there is variation in the way that Shared Lives carers are paid, and this could lead to difficulties for carers, especially if payments are not transparent, fair, or timely.

For Guideline Committee discussion of the evidence see the Evidence to Recommendations tables in Section 3.7.

Included studies for these review questions

Allen DG, Lowe K, Moore K et al. (2007) Predictors, costs and characteristics of out of area placement for people with intellectual disability and challenging behaviour. Journal of Intellectual Disability Research 51, 409–16

Barron D, Hassiotis A, Paschos D (2011) Out-of-area provision for adults with intellectual disabilities and challenging behaviour in England: Policy perspectives and clinical reality. Journal of Intellectual Disability Research 55, 832–43

Beadle-Brown J, Mansell J, Cambridge P et al. (2010) Adult protection of people with intellectual disabilities: incidence, nature and responses. Journal of Applied Research in Intellectual Disabilities 23, 573–84

Bigby C, Beadle-Brown J (2016) Improving quality of life outcomes in supported accommodation for people with intellectual disability: what makes a difference? Journal of Applied Research in Intellectual Disabilities, advance online publication doi: 10.1111/jar.12291

Brown RI, Geider S, Primrose A et al. (2011) Family life and the impact of previous and present residential and day care support for children with major cognitive and behavioural challenges: A dilemma for services and policy. Journal of Intellectual Disability Research 55, 904–17

Browning M, Gray R, Tomlins R (2016) A community forensic team for people with intellectual disabilities. Journal of Forensic Practice 18, 274–82

Curtis L (2011) PSSRU unit costs report. ‘Shared Lives – model for care and support’. Canterbury: Personal Social Services Research Unit, University of Kent

Davis A, Doyle M, Quayle E et al. (2015) ‘Am I there yet?’ The views of people with learning disability on forensic community rehabilitation. Journal of Intellectual Disabilities and Offending Behaviour 6(3/4), 148–64

Deveau R, McGill P, Poynter J (2016) Characteristics of the most expensive residential placements for adults with learning disabilities in South East England: A follow-up survey. Tizard Learning Disability Review 20(2), 97–102

Emerson E, Robertson J (2008) Commissioning person-centred, cost-effective, local support for people with learning difficulties (knowledge review 20). London: Social Care Institute for Excellence

Felce D (2016) Community living for adults with intellectual disabilities: unravelling the cost-effectiveness discourse. Journal of Policy and Practice in Intellectual Disabilities, advance online publication doi: 10.1111/jppi.12180

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Golding L, Emerson E, Thornton A (2005) An evaluation of specialized community-based residential supports for people with challenging behaviour. Journal of Intellectual Disabilities 9, 145–54

Harflett N, Pitts J, Greig R et al. (2017) Housing choices: discussion paper 1: What is the evidence for the cost or cost-effectiveness of housing and support options for people with care or support needs? London: National Development Team for Inclusion

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Joyce T, Ditchfield H, Harris P (2001) Challenging behaviour in community services. Journal of Intellectual Disability Research 45(2), 130–8

Kozma A, Mansell J, Beadle-Brown J (2009) Outcomes in different residential settings for people with intellectual disability: A systematic review. American Journal on Intellectual and Developmental Disabilities 114(3), 193–222

Lindsay WR, Holland AJ, Carson D et al. (2013) Responsivity to criminogenic need in forensic intellectual disability services. Journal of Intellectual Disability Research 57, 172–81

Mansell J, Beadle-Brown J (2004) Grouping people with learning disabilities and challenging behaviour in residential care. Tizard Learning Disability Review 9(2), 4–10

Mansell J and Beadle-Brown J (2009) Dispersed or clustered housing for adults with intellectual disability: A systematic review. Journal of Intellectual and Developmental Disability 34(4), 313–23

McConkey R, Gent C, Scowcroft E (2013) Perceptions of effective support services to families with disabled children whose behaviour is severely challenging: a multi-informant study. Journal of Applied Research in Intellectual Disabilities 26, 271–83

McGill P, Poynter J (2011) How much will it cost? Characteristics of the most expensive residential placements for adults with learning disabilities. Tizard Learning Disability Review 16(2), 54–7

National Association of Adult Placement Services (2009) A business case for Shared Lives. Liverpool: NAAPS

Pearson GS (2012) The transition experience of developmentally impaired young adults living in a structured apartment setting. Advances in Nursing Science 35: E73–89

Perry J, Allen D, Pimm C et al. (2013) Adults with intellectual disabilities and challenging behaviour: The costs and outcomes of in- and out-of-area placements. Journal of Intellectual Disability Research 57, 139–52

Pratt K, Baird G, Gringras P (2012) Ensuring successful admission to hospital for young people with learning difficulties, autism and challenging behaviour: A continuous quality improvement and change management programme. Child: Care, and Health & Development 38(6), 789–97

Robertson J, Emerson E, Pinkney L et al. (2002) Quality & Costs of Community-Based Residential Supports for People with Learning Disabilities and Challenging Behaviour. Lancaster: Institute of Health Research, University of Lancaster.

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Slevin E, Sines D (2005) The role of community nurses for people with learning disabilities: working with people who challenge. International Journal of Nursing Studies 42, 415–27

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3.2 Service capacity

Introduction to the review questions

The purpose of the review questions was to examine research about the capacity of services and the types of services there should be in the community and inpatient settings to meet the needs of children, young people and adults with learning disabilities and behaviour that challenges. This includes general and specialist support for people with learning disabilities and behaviour that challenges, including for people who may have come into contact with the criminal justice system.

In order to know this we need to look at what proportion of the whole population might need services, what the current service needs are and if these needs are currently being met.

Sometimes we can find this out by looking at what happens when services are not working as they should, for instance, when discharges from hospital are delayed, or when people are placed far away from home because there are no services available locally when needed.

Review questions

2.1. What is the appropriate community-based (including residential care) service capacity for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers?

2.2. What is the appropriate inpatient bed capacity (local and out of area) for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers?

Summary of the review protocol

Review questions that were developed in scoping phase were discussed with the Guideline Committee and formed the basis for developing the protocols for each question. Full protocols can be found in Appendix A.

Population

People with a learning disability and behaviour that challenges, parents, families or carers of people with a learning disability and behaviour that challenges. Professionals who work with people with a learning disability and behaviour that challenges.

Intervention

Community-based services, inpatient services.

Setting

All settings where care is delivered.

Person-focused outcomes

Child development outcomes; continuity of care; families' and carers' stress and resilience; frequency, severity and duration of behaviour that challenges; health and social care-related quality of life; inclusion in community life; service user involvement in planning, delivery and monitoring of services; service user, family and carer satisfaction.

Service-focused outcomes

Availability, access and uptake of local services; equity of access; meeting complex, physical and mental health needs; geographical variation in service provision (locally, regionally and nationally); level and type of support from care workers and carers; positive behaviour support; timely discharge; out-of-area placements; use of inpatient services.

Phenomena of interest (for views and experiences studies)

Barriers and facilitators to access to services; experiences of stress and resilience; preferences and values; involvement in the planning, delivery and monitoring of services; inclusion in community life; independence.

Study designs

Systematic reviews; randomised controlled trials; single group before-and-after evaluations; cross-sectional surveys; mixed methods; process evaluations; retrospective case note reviews; audits of current service use; views and experiences studies.

See Appendix A for full protocols.

How the literature was searched

A search strategy for all of the review questions combined was developed and the questions were translated into a framework of 5 concepts of: a) population (people with a learning disability and behaviour that challenges) and b) service provision (including models of services and service capacity) or c) risk management or safeguarding or d) integrated services or e) access to services. These reflected the question areas: types of service provision, service capacity, service delivery and integration of services. The search strategy was run between December 2015 and January 2016 and update searches were conducted between February and March 2017. See Appendix A for full details of the search.

How studies were selected

Results from the searches were stored in EPPI-review 4, a software program designed for information management of systematic reviews. The titles and abstracts of these results were screened against inclusion criteria that was developed from the scope. Two reviewers looked at the same studies' titles and abstracts independently of each other and compared their results to make sure that the inclusion criteria was understood and applied in the same way by both reviewers.

Studies that were found to meet the initial inclusion criteria were assigned to the relevant review question and the full text was retrieved for a second screening against the criteria in the protocol for this question.

After initial screening on title and abstract there were 131 studies that were relevant to the question on service capacity and these were located and retrieved for full text screening. After screening against the full text we retained a total of 30 studies. Eleven studies related to inpatient service capacity, 21 studies related to community capacity and 2 of these studies related to both inpatient and community capacity. Looking at the included studies another way, 7 studies related to general and specialist community capacity, 5 studies related to community forensic services, 11 studies related in inpatient service capacity and 9 studies looked at costs of services in the community and inpatient services.

Overall the study quality is low to moderate. The majority of studies were cross-sectional surveys. Compared to other study designs, surveys are prone to more sources of bias and are less reliable in their findings. However, they were the best kind of study to answer questions about current service needs and patterns and trends in service use. We looked for themes where more than 1 study found the same thing. This gave us more confidence in the reliability of the findings than from just 1 study.

The included studies (see below) were critically appraised using NICE tools for appraising different study types, and the results tabulated. Further information on critical appraisal is given in the introduction at the beginning of Section 3. Study findings were extracted into findings tables.

See Appendix B for full critical appraisal and findings tables.

Narrative summary of the evidence

Below are the narrative summaries of included studies, including economic and cost-effectiveness studies where identified.

Adams D, Handley L, Simkiss D et al. (2016) Service use and access in young children with an intellectual disability or global developmental delay: Associations with challenging behaviour

Review question(s): 2.1

Organisations authors involved with:

1. Cerebra Centre for Neurodevelopmental Disorders, School of Psychology, University of Birmingham, UK
2. Clinical Psychology, University of Manchester, UK
3. Division of Mental Health and Wellbeing, Warwick Medical School, University of Warwick, UK

4. Department of Social Policy, London School of Economics and Political Science, UK
5. Centre for the Economics of Mental and Physical Health, Kings College London, UK

Study aim

The aims of this study were to understand whether service use is higher or lower depending on child and parent characteristics, such as a child's demographics, level and type of challenging behaviour, self-injury, aggression and destructive behaviour, level of intellectual disability, level of adaptive ability and parent anxiety and depression.

Methods

This study used a cross-sectional design based on children living in the community. Child and parent dyads were recruited while parents were waiting for an appointment at a child development centre in a large UK city. A total of n=49 mothers participated. It is unclear how many were initially contacted so it is not possible to calculate a response rate (nor do the authors provide one).

Only healthcare service use was measured. The study does not measure the use of unpaid caregiver hours, education services or social services (p3). Mothers were provided with the Client Service Receipt Inventory for Children with Intellectual Disabilities (CSRI-CID), which asks them to report the frequency of healthcare services accessed in the past 6 months (p3). Appropriate methods were used to estimate total costs, including the appropriate use of unit costs of healthcare services, which were taken from the PSSRU compendium. Prices reflect 2012/13 year.

Sample characteristics

Sample characteristics of the n=49 child–parent dyads included children aged 2–9 years (mean 6.6 years, sd=2.7). A majority of the children were male (75.5%). A majority of the child sample were white (67%) with the remaining from a mixed background (12.5%), south Asian (14.5%) and black Afro-Caribbean background (4%). All of the children lived at home with their biological parents.

A majority of the children had a diagnosis of intellectual disability (73.5%) and the remaining had a diagnosis of global developmental delay (26.5%). Other diagnoses included autism (24.5%) or having autistic traits (14.3%) (as reported by parents).

Findings

Patterns of service use (costs)

In the past 6 months, the average total healthcare costs per child were £451.65 (sd=£414.49) with a range from £46.33 to £1699.55. Hospital costs comprised approximately 20% of costs (average £89.49, sd=£208.35, range =£0–£1160), and the remaining 80% were from community-based healthcare services (average £362.16, sd=£328.95, range =£34.50–£1282.33) (p4). The most frequently contacted professionals were paediatricians, general practitioners, and speech and language therapists.

Results – associations between child and parent characteristics and service use (costs)

There was no relationship (no statistically significant difference) between costs/services used and child characteristics such as age, gender, ethnicity, diagnosis of autism, adaptive ability, overactivity, impulsivity, number of challenging behaviours or health problems (p5).

There was also no relationship between parent anxiety or depression and child's use of healthcare services/costs (p7, Table 2).

When comparing the impact of the three most common types of challenging behaviour, analyses found that children with challenging behaviour with aggression (n=41) had higher costs (£494.03, sd=436.10) (large effect size, Cohen's d=0.67) than children with challenging behaviour without aggression (n=8) (£234.42, sd=164.60) (p<0.007). Children with aggression had higher costs as a result of using more community services (p<0.001). They did not differ in their use of hospital services (p=0.77).

Children with challenging behaviour and were also destructive of the environment (n=31) had higher costs (£554.63, sd=472.3) (large effect size, Cohen's d=0.71) than children not destructing of the environment (n=18) (£274.28, sd= 196.90)(p<0.006). Children that were destructive of the environment had costs were because they used more community services (p<0.01). They did not differ in their use of hospital services (p=0.24).

Children with challenging behaviour showing self-injury (n=23) had the same costs (£520.92, sd=414.40) as children without self-injury (n=26) (£390.92, sd=414.40) (p=0.30) (p.5-6). Self-injurious children had slightly higher costs because they had slightly higher use of community services (p<0.09). Children with and without self-injurious behaviour did not differ in the use of hospital services (p=0.53).

The study also found a trend towards (but not statistically significant) relationship between the number of different types of challenging behaviour (none to three) and costs (p=0.07) (small effect size, Cohen's d=0.27). Children with none (n=5) or 1 form of challenging behaviour (n=10) had costs of £248.93 (sd=192.80) and £206.09 (sd=134.60) over a 6-month period whereas children with 2 (n=17) or 3 (n=17) forms of challenging behaviour had costs of £536.85 (sd=465.30) and £570.85 (sd=454.00) over a 6-month period. Children with 2 or 3 forms of challenging behaviour had higher costs because they had greater use of community services (p=0.04). The use of hospital services was the same regardless of the number of forms of challenging behaviours (p=0.64).

Conclusions and considerations

In conclusion, children with challenging behaviour that display aggression or destruction of the environment use 1.9 and 2.5 times more community-based services than children with challenging behaviour not displaying those behaviours. There were no differences in their use of hospital services.

Children with and without self-injurious behaviour did not have different patterns of community or hospital service use.

Children with two or three forms of challenging behaviour use approximately 2 times more community-based services than children with 0 or 1 forms of challenging behaviour. The authors conclude that this suggests a need for effective and accessible early intervention services (p.8).

Considerations

This study is based on a small sample from 1 large UK city; therefore, findings are not generalisable to the rest of the UK and require further research. Furthermore, this study does not measure the impact of children's or parents' characteristics on the use of social or education services or the impact on informal care provided. Future studies should include this in research.

Allen DG, Lowe K, Moore K et al. (2007) Predictors, costs and characteristics of out of area placement for people with intellectual disability and challenging behaviour

Review question(s): 1.1, 2.1

See narrative summary in section 3.1 for economic narrative summary.

Barron D, Molosankwe I, Romeo R et al. (2013) Urban adolescents with intellectual disability and challenging behaviour: costs and characteristics during transition to adult services

Review question(s): 2.1 (economic narrative summary)

Organisations the authors are involved with:

1. Research Department of Mental Health Sciences, University College London Medical School, London, UK

2. Health Service and Population Research, Centre for the Economics of Mental Health, Institute of Psychiatry at King's College London, London, UK

Type of study: observational study

Country: UK

Population: adolescents with intellectual disability and challenging behaviour

Quality score: +

Aims

Aims

Barron et al (2013) undertook an observational study to understand the patterns of service use and cost among adolescents aged 16-18 years with intellectual disabilities and behaviour that challenges who are transitioning into adult services.

Methods

This study is based on the findings of n=27 individuals in 1 inner London borough between 2006 and 2008. These 27 represent the families and young people who agreed to take part in the study, out of a total eligible sample of n=31 (87%) (pp286–7).

Individuals' level of intellectual disability was determined using local service criteria, based on recorded clinical notes (p285). Individuals were classified into mild, moderate and severe intellectual disabilities.

Additional measures were collected, including the following.

Mental status

Using the Strengths and Difficulties Questionnaire (SDQ) (measures conduct disorders, hyperactivity and emotional disorders, and also includes peer relationships and prosocial behaviours).

Using the Mini PAS-ADD (measures 86 psychiatric symptoms, but in this study it was used to assess for presence of psychosis and autism).

Challenging behaviour

Using the Challenging Behaviour Checklist (CBC).

Service use

Using the Client Service Receipt Inventory (CSRI) which measures:

- use of health and social care services,
- accommodation and living situations,

- income,
- employment and benefits,
- carer data (hours supporting the service user directly; hours taken off work to support the service user).

Individuals provided information relating to the past 6 months. Information on inpatient admissions was verified by checking hospital records. School attendance and absence was estimated using national statistics relating to individuals with intellectual disabilities in transition (p286).

Findings – demographic information

The sample comprised 52% males.

In relation to level of intellectual disability, there were 41% with mild, 41% with moderate and 18% with severe intellectual disabilities (p286).

(Note: text reports that 2/3 of the sample had severe intellectual disabilities, but there is a discrepancy with the information provided in the table, which shows 18% of the sample with severe intellectual disabilities.)

In relation to challenging behaviour (p287):

For the severity of challenging behaviour:

- average score was 16.8, sd=11.1, range 0-36 (CBC),
- n=3 (11%) individuals had a score of 0,
- n=15 (55%) had a score of 17+.

Number of challenging behaviours:

- n=18/24 had 2+ challenging behaviours,
- n=5 had no challenging behaviours at the time of interview.

(Note: it is not clear why there is a discrepancy in sample size total – here, the sample size adds up to n=29, rather than n=27.)

Most lived in parental home (70% n=19,), out-of-area specialist residential (19%, n=5), foster care (7%, n=2) and supported accommodation (4%, n=1) (p286); 89% were in full time education (n=24/27) (p287).

Education was provided in-area for n=11 individuals, while n=13 were placed in another London borough, and n=4 were placed in education outside of London (p287). (Note: it is not clear why figures add up to n=28, instead of n=27).

A total of 18 (66%) had at least 1 physical diagnosis (p.287), n=23 (85%) had mental health difficulties (mean score of 19.81, sd=6.86, on the SDQ) (p287), n=9 (33%) individuals were on the autism spectrum (p287).

There was a significant positive association between mental health and challenging behaviour, where individuals with higher levels of challenging behaviour also had higher scores on the SDQ (p288).

Likewise, there was a positive association between having autism and challenging behaviour, where individuals with autism had higher scores on the severity of challenging behaviour (p288).

Findings – service use and costs

Links between characteristics and costs (p289)

Statistical analyses showed no association between costs and:

- level of challenging behaviour (p=0.233),
- complex cases (that is, total number mental and physical diagnoses) (p=0.244).

There was a significant association between costs and level of intellectual disability (p=0.018). Severe intellectual disability was associated with higher costs.

Main contributors to total cost (p289)

Total average cost was £2,543/week, based on the average use of services across the sample of n=27 adolescents. Informal care was on average 86 hours per week. If this were paid by the public sector, using the unit cost of a professional home care worker, then this would sum to £1,554 per week, making this the largest cost category (66%).

Education was the second largest cost category, comprising 22% of costs (£560/week). Community-based services comprised 8.7% of costs (£221.14/week), followed by hospital services, 0.4% (£10.97/week). Daytime activities comprised 3.4% of costs (£87.35/week).

Pattern of service use (p289)

Daytime activities

Total 96% of adolescents used daytime activities (n=26/27), including 48% using social clubs (n=13), adult education (n=5, 19%), day centre (n=4, 15%) and drop-in centre (n=2, 7%). Community-based services most frequently used in the past 6 months were:

- social worker (85%, n=23),
- dentist (67%, n=18),
- speech and language therapist (63%, n=17),
- Art/drama/music therapist (44%, n=12),
- GP (41%, n=11),
- other community nurse (41%, n=11).

Community services least frequently used in past 6 months:

- community psychiatric nurse (4%, n=1),
- intellectual disability nurse (4%, n=1),
- chiropodist (4%, n=1),
- occupational therapist (15%, n=4),
- alternative therapist (19%, n=5),
- advocate counsellor (22%, n=6),
- optician (22%, n=6),
- home help/home care worker (26%, n=7),
- clinical psychologist (26%, n=7),
- psychiatrist (30%, n=8),

- other community services (37%, n=10).

Hospital-based services used in past 6 months:

- n=1 individual (4%) using inpatient services,
- n=2 individuals (7%) using A&E,
- n=6 individuals (22%) using outpatient services.

Education in past 6 months:

- most individuals were in day schools,
- special needs schools (70%, n=19),
- mainstream schools (15%, n=4),
- small number were in residential schools (15%, n=4).

Employment in past 6 months:

None of the adolescents accessed employment services.

Informal care

Most carers were women (n=24/27), 70% were mothers (n=19/27) and 40% of carers were living with another partner or were married (n=11/27).

Besides having unpaid care, n=6 (22%) individuals also had an additional 6 hours of support per week from other friends and family; n=7 (26%) carers were in employment, and the remainder were either unemployed or housewives; n=12 (44%) reported giving up work to support the young person (p290).

N=5 carers also cared for elderly relatives, n=15 also cared for other children.

Economic considerations

The methods of estimating costs (service use and unit costs) were appropriately conducted and transparently reported.

Limitations of the study

Caution is advised before generalising findings as this study is based on a small sample of individuals in 1 inner-London borough.

Individual outcomes, such as quality of life, were not measured. Likewise, the impact on carers' outcomes was also not measured.

Beadle-Brown J, Mansell J, Whelton B et al. (2009) People with learning disabilities in 'out-of-area' residential placements: views of families, managers and specialists

Review question(s): 2.1

Organisations the authors were involved with:
1. Tizard Centre, University of Kent
2. The Avenues Trust

Type of study: Qualitative study of views and experiences

Country: UK

Population: Home managers, care managers or reviewing officers, family carers, adults with learning disabilities and behaviour that challenges who were placed within 1 local authority in the South East of England

Quality score: +

Type of service: Residential placements

Aim of study

The study wanted to answer the following questions.

Do family members and care managers report difficulties in finding a suitable placement?

Are there difficulties in contact for family members and in contact and communication between care managers and the person themselves, the home manager and professionals in the receiving area?

How is the quality of out-of-area placements viewed by family members, care managers and professionals in the receiving area?

Are there advantages to such placements? (p17)

Findings

We grouped what staff and families said about out-of-area placements into themes.

Accountability

Staff said that it was difficult to find someone to take responsibility if anything went wrong.

'… and yet as soon as it starts going wrong you can't contact the person that's placed to get them to come down and assist'. (Occupational therapist, p24)

Families said that they were afraid of complaining or raising issues.

'There's lots of things I'd like to say but I'm frightened to because sometimes what I've said has been misinterpreted and it has come back that I've been having a dig at them.' (Family member) (p24)

Staff said that there wasn't enough monitoring because sometimes the quality of the care was poor and without monitoring would get worse over time.

'… because there isn't the support from the placing authority in a lot of cases, unless its crisis driven, things are let slide that shouldn't be let slide'. (Psychologist) (p25)

Access to support

Six of the 9 care managers who could give a reason for the placement being out-of-area said this was because there wasn't access to the same type of placement locally.

The reason given for 8 of the 26 people placed out-of-area was because specialist services were not available locally.

‘Services within the borough are very limited and sometimes you need specialist services that are only available out of borough, then we would place out of borough’ (Care manager) (p22).

Choice and control

Families said that they didn’t feel that they had much of a choice. Sometimes this was because a decision had to be made in an emergency. But families who did have a chance to be involved in the decision-making were a lot happier with the placement.

‘We were given the choice, not made to feel that this was the only placement she could go to’ (Family member) (p22).

Environment

Community support teams described the environment of the home as institutional.

‘… just horrible, grey, dirty, depressing environments. It takes you back years’ (Speech and language therapist) (p26).

Family life

Being placed out-of-area can make family visits difficult, even if there is funding to visit available.

‘[her sister] has to contact them and say that she’s coming down … and they will give her a travel warrant but they won’t give them for her children and she can’t come without her children, they obviously haven’t got a lot of money’ (Home care manager) (p23).

Information

None of the community disability teams felt that they could access the right information about the people they were taking. They said that either the assessments weren’t done properly, or they couldn’t get access to them.

Impact on carers

Family carers were faced with little real choice. The options were to accept the placement out-of-area on offer, or take on full-time caring responsibilities themselves if they were unable to accept the placement.

'… Oh I was told that I could have the money … if I could look after him myself … What a crazy idea … I couldn't look after him, I was working' (Family member) (p22).

Navigating care services

Family carers said that they had to challenge the decision to get the care that was suitable for their family member.

'… because I think that everything we have got we have had to fight for. They make you jump through hoops for it …' (Family member) (p23).

Staff sometimes said it was difficult finding time to be able to work together with other professionals because of being so busy.

'It's just really hard to get hold of people, everyone's in meetings, they have the same problem getting hold of me really' (Care home manager) (p23).

Resources

Even though the home may be charging high fees for its service, and say that it was a specialist service, some community learning disability teams felt that in fact it was they who were looking after people's needs. Because people who are placed out-of-area are more likely to have high and complex needs, this means that local community teams have to spend more time looking after them. Some community staff said that this takes time away from clients who live locally.

'The team want … to be very proactive … and we just can't because the out-of-area clients are so challenging they take up the majority of the time. When they go into crisis, they go into a major crisis' (team manager) (p27).

Safety

When there isn't monitoring of the quality of the service over time, this means that people can be at risk of poor care, and it won't be noticed.

Satisfaction

Fourteen of 15 families interviewed said that they thought their relative was happy living in the home.

'In general the service is good. They have long-term staff which is good' (family carers).

Staff skills

Family carers often said they were happy with the placement, and that staff had skills and knowledge to help their relative learn new skills and that the relative was well looked after, however, staff and community teams did not always agree with family carers that the level of care was adequate.

'One staff to five people and these are very high need complex residents with learning disability and it's permissible. We are told that is perfectly acceptable. But it's these out of area homes that use that, that work to that standard. Minimum standard' (senior nurse practitioner) (p25).

Considerations

The study was conducted in 1 local authority area in the South East of England. This is a large area that includes both urban and rural areas, as well as areas of high and low property prices that might affect the availability of accommodation with support. This local authority area is more likely to have people placed out-of-area than other areas.

There were no direct quotes from people with learning disabilities and behaviour that challenges in the study, and it's not clear how many views and experiences of people who stayed in the homes were included in the study, although the authors tried to make sure that the sample was balanced in terms of demographic characteristics and to ask consent from people who lived in the homes. There was no further analysis to see if demographic characteristics made a difference to what families and care managers said. A further analysis of what people who lived in the homes said about their experiences is in a linked study by the same authors (Beadle-Brown et al. 2006).

Browning M, Gray R, Tomlins R (2016) A community forensic team for people with intellectual disabilities

Review question(s): 1.1, 2.1

See narrative summary in section 3.1.

Buxton L, Pidduck D, Marston G et al. (2004) Development of a multidisciplinary care pathway for a specialist learning disability inpatient treatment and assessment unit.

Review question(s): 2.2, 3.1, 5.1

Organisations the authors were involved with:
1. Whitefriars Lodge
2. River House, Gulson Hospital

Type of study: this is a process evaluation study, which means that the authors looked at how a programme, service or initiative could be done, but not whether it was effective in practice – process evaluations can be useful to understand how to put something into place if a service is effective as it can suggest why and what needs to happen for a service to work

Country: England, UK

Population: People with learning disabilities and mental health problems or behaviour that challenges

Quality score: -

Type of service: A specialist learning disability inpatient treatment and assessment unit

Aim of study

The study aimed to identify all the various members of the multidisciplinary team and the wider health and social care community involved in the process of assessment and treatment. The admission and assessment process was then analysed retrospectively, looking for things that had caused a delay in the process or areas of concern such as risk management, where documentation needed to be developed.

Findings

The authors say that this process has been in place for 2 years and is going to be formally evaluated. They say that this process has prevented people being transferred out-of-area and a much wider range of professionals are involved in the care pathway.

Key features of the service

Assessment reports and intervention plans

Information use/sharing

This includes the use of the 'Health of the nation outcome scale for people with a learning disability' (p122). This is a tool designed to measure change in a number of domains and this assessment is now carried out prior to admission and then at a number of points during the care pathway.

Protocols

A unit information booklet and joint observation policy between medical and nursing staff includes levels of recording, a physical intervention risk assessment, a physical observation recording chart, ongoing risk assessment and management plans, a basic living skills assessment, a structured pre-discharge package and a pre-discharge checklist.

Why it worked

A time limit of 12 weeks was decided on, other than in exceptional circumstances. This provides a clear end-point to the admission and assessment process.

What also helped

Documentation was developed to support the pathway, including a pre-admission assessment document, where the history of the presenting condition was recorded and a preliminary risk assessment carried out prior to admission.

Multi-agency-interdisciplinary involvement

What got in the way

Capacity, such as the availability of suitable residential accommodation in the community. Factors outside the inpatient unit are the primary reason for the pathway not being followed.

Considerations

We have already looked at this study for the models of system-focused care, but it is also relevant to the capacity question, as it describes what can be done to prevent out-of-area placements, which can happen when there isn't the right care available at the right time.

The study describes the development of the care pathway process and is relevant to this review. The study does not report on the impact of adopting the care pathway or how scalable the process would be for other treatment and assessment units.

We were not able to find the formal evaluation of the care pathway that was discussed in the article.

Chaplin E, Kelesidi K, Emery H et al. (2010) People with learning disabilities placed out of area: the South London experience

Review question(s): 2.2

Organisations the authors were involved with:

1. Behavioural and Developmental Clinical Academic Group, Institute of Psychiatry King's College; London

2. Estia Centre, South London and Maudsley NHS Foundation Trust, Kings' Health Partners, UK

Type of study: A mixed methods study – a retrospective review of hospital records to identify people who were placed out of area and their characteristics, and interviews with people who use services

Country: UK

Population: People with learning disabilities and mental health problems – challenging behaviour was present in 41% of the group

Type of service: High, medium and low secure forensic beds and step-down facilities

Quality score: +

Study aim

The study looked at the demographic, clinical and offending characteristics of people with learning disabilities placed out-of-area in South London. The second part of the study compared the needs and quality of life of the out-of-area group with another group receiving services locally.

Findings

Characteristics of people placed out-of-area – people placed out of area experienced:

- more ‘behaviour problems than others
- more problems with daily activities inside their living environment
- a significantly higher total number of needs
- more contact through telephone, letters etc. from family and friends
- less frequent visits from family and friends.

However, there was no significant difference between the 2 groups with regard to: self-harming behaviour and other behavioural problems that did not involve aggression to others. There were problems with relationships, communication, engagement in activities outside home, involvement in occupational and leisure activities and level of self-care skills. There were monthly visits from professionals such as social workers and care managers.

Reasons why people were referred out-of-area

There were 3 distinct reasons o why people were initially placed out-of-area: they had committed an offence (46%); they had challenging behaviour and antisocial behaviour (34%); they had a severe mental illness (21%).

Where were they placed?

Specialist residential care (43%), medium security (32%), low security (21%). The study also found that people moved on average 3 times between out-of-area placements and the average distance from home was 78.57 miles, though there was a wide variation in distance.

Outcomes for people out-of-area

In terms of quality of life, there was no significant difference between people placed in-area or out-of-area. However, when it comes to ‘independence and empowerment’ there was a slight trend, suggesting that a larger sample would be able to detect that the people receiving services out-of-area were less independent and empowered than people receiving local services.

In terms of having their needs met, people who were in out-of-area placements had a significantly higher total number of needs than the locally-treated group. However, there were no significant differences between the 2 groups in regard to their met needs, current unmet needs or the proportion of their needs being met.

Considerations

The study is small scale and confined to inner London. The researchers found it difficult to recruit participants for the main study, and as a result only 28 out-of-area participants took part. So we cannot be sure that the same characteristics of people placed out-of-area and the outcomes found in this study would be the same for others in the UK.

We can be more certain about the reasons why people were placed out of area because they have been identified in another study (Chaplin and Xenitidis 2010). These include: committed an offence; challenging behaviour and antisocial behaviour; and severe mental illness. The authors suggest that local care pathways are needed to reflect the needs of the 3 groups and local commissioners could consider these risk factors for out-of-area placements and use this knowledge to help ensure the right capacity in local services.

The authors suggest some findings that came as a surprise because they weren't mentioned in other parts of the study, for example, page 10 says ‘This study found that younger males and those with offending behaviour were more likely to be placed out of area’. While it is clear that people with offending behaviour were more likely to be placed out-of-area, reference to the age of participants is not mentioned elsewhere in the study so we cannot verify that they were also ‘younger’.

An interesting finding was that half (50%) of those living locally never had a visit from a social worker or case manager compared to a quarter (25%) of those placed out-of-area, which suggests an unmet need in the ‘in-area’ group for social care.

It is worth noting that resources from local services are significantly consumed as a result of out-of-area placements due to monitoring commitments – for example, involvement and visits from case managers – and need to be considered when planning services.

Devapriam J, Alexander R, Gumber et al. (2014) Impact of care pathway-based approach on outcomes in a specialist intellectual disability inpatient unit

Review question(s): 2.2, 3.1, 5.1, 5.2

Organisations the authors were involved with:

1. Leicestershire Partnership NHS Trust, UK
2. University of East Anglia, UK

Type of study: This is an evaluation of a single group

Country: England, UK

Population: People with learning disabilities and behaviour that challenges or mental health problems who were admitted into a specialist learning disability inpatient treatment and assessment unit

Quality score: -

Type of service: A specialist learning disability inpatient treatment and assessment unit

Aim of study
To evaluate the impact of a care pathway-based approach on treatment and quality of care outcomes before and after the implementation of the new approach.

Findings

Clinical outcomes

Physical health

Mean (sd) average HoNOS-LD scores on admission – pre-pathway 19.4, post-pathway 21.5 ns. On discharge – pre-pathway 5.1 post-pathway 3.2 ns.

Service use

Length of hospital stay

Mean (sd) average length of stay: admission until medically fit for discharge pre-pathway 77 (28.4), post-pathway 20.4 (20.5) p<0.000. Admission until actual discharge: pre-pathway 148.2 (179.2), post-pathway 7.8 (24.7) p< 0.008. Discharge delay (mean days) pre-pathway 131.3 (180.4), post-pathway 8.4 (15.7), p<0.000.

The authors say that they found that the average length of hospital stay for patients was reduced. As a result, there was a threefold increase in the number of admissions to the inpatient unit because the unit was able to accommodate all patients with intellectual disability who needed inpatient care. This also suggests that before the care pathway approach was implemented, people might have been transferred out-of-area as there were no beds available for them at this unit.

Key features of the service

Coordinator

The coordinator was a band 6 nurse pathway coordinator with the sole responsibility of ensuring progress of patient journey through the pathway by working jointly with the relevant agencies and professionals.

Summary

Why it worked

Care pathways outline the essential steps in the care and treatment delivered for a patient, including anticipated care over a given time period and documentation of milestones and clinical interventions throughout the patient's clinical experience.

What also helped

Collaborative teamworking

Good joint working with local authority colleagues and clinical commissioning groups in achieving less delay in discharge from hospital for patients into the community.

Regulation

A clear framework of timescales and responsibilities that incorporates policies and guidance that are relevant across health and social care boundaries and that make individual professionals accountable to deliver on their duties for patients.

Multi-agency–interdisciplinary involvement

Working jointly with community teams

Regular review

Monthly meetings were held with stakeholders from clinical commissioning groups, NHS England, respective local authorities and inpatient and community staff from provider services to review the care and progress of patients in the unit.

Single coordinator

Effective inter-agency working can be achieved by employing a dedicated band 6 nurse in this role due to the nature and amount of work involved.

What got in the way?

No barriers to implementation of the care pathway approach were discussed.

Considerations

The study was relevant to us; it looked at some things that help us answer the questions we have asked.

The study was only looking at the impact after implementation for 1 assessment and treatment unit over a short period of time. Without comparing to another typical assessment and treatment unit it is not clear whether this care pathway would be a good approach for every assessment and treatment centre.

The study looked at only a few key outcomes. There may be other reasons why the approach seemed to perform so well at the unit, such as characteristics of the unit itself, like staff morale, organisational culture and leadership styles, resources and the capacity of community services to absorb the earlier discharges without causing bottlenecks and delays.

Deveau R, McGill P, Poynter J (2016) Characteristics of the most expensive residential placements for adults with learning disabilities in South East England: a follow-up survey

Review question(s): 1.3, 2.1, additional economic analysis on housing

See narrative summary in section 3.1.

Gangadharan S, Bretherton K, Johnson B (2001) Pattern of referral to a child learning disability service. British Journal of Developmental Disabilities 47(2): 99–104

Review question(s): 2.1

Organisations the authors were involved with:
1. Greenwood Institute of Child Health, Leicester, UK

Type of study: Cross-sectional study, secondary data study

Country: UK

Population: Children referred to a specialised learning disability team in Leicestershire

Type of service: Learning disability intensive support team

Quality score: -

Study aim

Describe how a specialised learning disability team integrated into the Child and Adolescent Mental Health Service (CAMHS) works. To describe the demographic characteristics, nature of the disabilities and the referral reasons of the children referred to the team over an 8-month period.

How the service works?

The learning disability team is located within (CAMHS) provides care and treatment for children with a moderate, severe or profound learning disability. The team includes a consultant, 2 full-time community psychiatric nurses, a part-time psychologist and a secretary. Integration of the team with CAMHS means that the team have access to services like family therapy and a day centre – where children's interactions can be assessed – and group sessions. There is also access to a paediatric neurologist.

Cases are allocated at a fortnightly multidisciplinary team meeting and 1 clinician takes on the role of case manager, even though it is often the case that more than 1 person will be providing care. A separate home intervention service has also been set up to help families with children's behaviour in the home.

Findings

Patterns of referral

A total of 63 children were referred and 50 were seen in an 8-month period. Referrals came from: 24% general practitioners; 32% paediatricians; 12–19% social workers; 10–16% educational services/other professionals.

Overall, 59% of children were referred for aggressive behaviour, however children presented with a wide variety of problems such as eating difficulties, toileting difficulties, issues related to compliance at school and home, self-injurious behaviour, repetitive obsessive behaviour and sleep problems.

Characteristics

The mean age of children using the service was 9.36 years, however 10% were aged 16 or above; 63% of children were boys; 49% of children had moderate learning disability and 47% had severe or profound disability; 45% of children had epilepsy and 35% had an autistic disorder; 2-thirds of children had multiple disabilities (autism, speech and language difficulties or epilepsy).

What helps the service work better?

The co-location with CAMHS and access to the multidisciplinary team is really beneficial to this population of children that have multiple disabilities and complex needs. This is especially the case for the 45% of children with epilepsy, where the assessment of behaviour problems is difficult because of the complex interactions between uncontrolled epilepsy, anti-epileptic medications and behaviour. Access to the joint neurology clinic in this study was really helpful.

It is difficult for generic CAMHS services to assess and manage the support needs of this group, therefore having a specialised child learning disability service with access to multidisciplinary support helps to provide a better service for the child.

Considerations

This study gives the broad picture of the patient population attending a child learning disability service for children with moderate, severe or profound learning disability. While the study doesn't mention the level of 'challenging behaviour' in the population, 59% of children were referred to the service for challenging behaviour so the service is relevant to our population. As the study only covers 1 service that works in a specific way we can't be sure that other children's learning disability teams would have similar patterns of referral.

This study doesn't tell us if having a specific service for children with learning disabilities integrated with CAMHS provides better outcomes for children or if it is a more effective way to provide services for children. It does show that there is a sizeable population of children with learning disabilities that have multiple disabilities and behavioural problems with multiple support needs who would benefit from having access to a specialised learning disability team.

Hall I, Yacoub E, Boast N et al. (2014) Secure inpatient services: a needs assessment

Review question(s): 2.2

Organisations the authors were involved with:
1. East London NHS Foundation Trust, London, UK
2. East London Forensic Service, London, UK
3. North London Forensic Service, London, UK

Type of study: Cross-sectional survey. This study identifies people who meet the inclusion criteria, then invites them to complete a survey

Country: London, UK

Population: People with learning disabilities in secure inpatient care

Quality score: +

Type of service: Forensic and secure learning disabilities services for people with learning disabilities and offending behaviour or severe challenging behaviour

Aim of study: The project objectives were to:

- agree a definition set for what constitutes forensic and secure learning disabilities services
- identify those originating from London currently using secure inpatient services
- make a basic assessment of their needs
- make predictions about the future need for secure services for people with learning disability
- further understand the commissioning and provider landscape.

Developing a commissioning strategy

The authors asked a reference group to help them interpret the clinical data. The reference group were clinicians with experience of both secure care and community services from a range of services in London.

The authors identified 249 patients from 6 NHS and 21 independent sector providers. Data was collected on 148 patients and 136 were judged by the reference group to have a learning disability.

Findings

Characteristics

Like other studies, this study found that people from the black and minority ethnic groups were over-represented (27% in this study compared to a population figure in London of 11%). Most were in the 24–28 age group, most (69%) had a diagnosis of a mild learning disability and only 31% of people who had been referred because of an offence had been convicted. Challenging behaviour was the most common reason for admission to hospital for female patients. For male patients it was for violence, challenging behaviour and a sexual offence.

Service needs

There was a greater need for low secure settings than medium secure settings. Most of the patients requiring medium secure care (n=45) required a ‘forensic’ type of care – that is, the behaviour that challenges was offending behaviour instead of behaviour that challenges that people are not held legally accountable for.

Local authorities are often the leads in commissioning secure services for people with learning disabilities but may not have the expertise to get services appropriate for people with forensic needs.

The needs assessment and mapping of service exercise found that there is a severe shortage of low secure beds in the NHS, and many people are placed in private facilitates far from home (82% were over 50 miles away from home).

The authors say that different types of care should be integrated so that patients can move when appropriate to less restrictive settings (‘step-down’).

What gets in the way?

The needs assessment and mapping exercise found that around 1 in every 6 patients could not progress due to a lack of ward, facility, resource and/or intervention. Reasons for this were: waiting to start an offending behaviour programme, waiting for an appropriate placement to be found, waiting on the outcome of a referral and (in 1 case) waiting for a psychology department to be formed.

Considerations

The authors were not able to get all the data they wanted, especially from the low secure units. This missing data was more often from independent providers. As is the case with surveys, they rely on the willingness of people to take part and sometimes they might want to give a particular impression of the service they represent.

Different services were not always described in the same way, such as those described as ‘long term’ or rehabilitation, and even what was meant by ‘level of security’ wasn’t always consistently applied, making direct comparisons difficult.

The people who were identified for this study were already in the secure care system, and we cannot know the needs of the hidden group of people who are not yet in, or may be at risk of entering, the secure care system.

Hassiotis A, Parkes C, Jones L et al. (2008) Individual characteristics and service expenditure on challenging behaviour for adults with intellectual disabilities

See narrative summary in section 3.5.

Review question(s): 2.1

Health and Social Care Information Centre (2015) Learning Disability Census report: England 30 September 2015 experimental statistics

Review question(s): 2.2

Type of study: This is an audit of inpatients with learning disabilities, autistic spectrum disorder and/or behaviour that challenges, and the services they receive, for patients who were inpatients in NHS and independent sector services at midnight on 30 September 2015

Country: England, UK

Population: People with learning disabilities, autistic spectrum disorder and/or behaviour that challenges

Quality score: +

Type of service: A specialist learning disability inpatient treatment and assessment unit

Aim of study

The principal aim of the Learning Disability Census is to deliver action 17 in ‘Transforming Care: A national response to Winterbourne View Hospital’ – an audit of current services for people with challenging behaviour to take a snapshot of provision, numbers of out of area placements and lengths of stay.

The census takes a snapshot of those people receiving inpatient care who had a learning disability, autistic spectrum disorder and/or behaviour that challenges on 30 September 2015.

Findings

On the 30 September 2015, 3000 patients were receiving inpatient care who had a learning disability, autistic spectrum disorder and/or behaviour that challenges.

Diagnostic category

A total of 2370 patients (79%) were recorded as having a learning disability, and 1160 patients (39%) were recorded as having autism; 710 patients (24%) were recorded as having both diagnoses.

Age

Total 92% of patients (2755 patients) were aged 18–64, substantially higher than the comparable proportion England-wide (59%); 6% of patients (165 patients) were aged ‘under 18’, much lower than the comparable proportion of England’s general population (24%).

Gender

Total 75% of patients (2255 patients) were male, much higher than the comparable proportion for England (49%). Females were more likely than males to be receiving care on a mixed gender ward; 38% of females (280) were on a mixed gender ward in 2015 compared to 20% of males (445).

The number of patients with no single sex space of any kind continued to increase to 45 patients (6%) on census day 2015, from 14 patients on census day 2013 (2%) and 35 patients on census day 2014 (4%).

Setting

Total 2255 patients (75%) were on a ward designated for people with learning disabilities; 665 patients (22%) were on a ward designated for mental health and 80 patients (3%) were on ‘other wards’.

Security level

Total 1575 patients (53%) were receiving care in general wards; the highest proportion in all 3 census collections. The proportion of patients receiving care in low secure wards reduced to 27% (810 patients) compared to 37% (1195 patients) and 31% (1015 patients) on census day in 2013 and 2014 respectively. Otherwise, the split between the different ward security levels remains unchanged between 2013, 2014 and 2015 census collections. In 2015 there were 25 patients (1%) receiving care in a ‘psychiatric intensive care unit’; 525 patients (17%) were receiving care in ‘medium secure’ and 70 patients (2%) were receiving care in a ‘high secure’ setting.

Provider

Total 1650 patients (55%) were receiving inpatient care with NHS providers, and 1350 (45%) with independent sector providers.

Reason for being in inpatient care

Total 2340 patients (78%) were recorded as having a treatment reason that indicated they needed inpatient care; 380 patients (13%) did not need inpatient care for treatment; 7% of this was because a new community placement was being sought as the previous placement was no longer viable; 6% was because ‘local step-down placement in inpatient psychiatric unit preparatory to community resettlement [was] being actively sought’.

Overall, 280 patients (9%) had a response of ‘other’.

Total 2050 patients (68%) had a care plan status that suggested that the patient needed to remain in inpatient care, and 950 patients (32%) had a care plan which did not suggest a need for inpatient care. The proportion of inpatients who needed inpatient care according to the care plan has risen slightly for each census collection from 66% in 2013, to 67% in 2014 and 68% in 2015.

Risky behaviour

Total 2505 patients (84%) had at least 1 or more risk present and approximately 805 patients (27%) had at least 1 risk present severe enough to require hospital treatment. A further 495 patients (17%) had been assessed as being too high risk for the Ministry of Justice to agree any reduction in security level. Results are in line with those for the 2013 and 2014 collections.

Distance from home

The average distance from home remained stable between the 3 censuses. The median distance from home on census day 2013, 2014 and 2015 was 34.5km, 34.4km and 38.6km respectively. Total 1645 patients (57%) were receiving inpatient care up to 50km from home; 1225 patients (43%) were receiving inpatient care 50km or more away from their home.

Those further from home tend to have longer hospital stays – 245 (37% of patients) staying 100km or more had a length of stay of up to a year. The remaining 425 patients (63%) in this distance band had a length of stay over a year. Except for the distance banding 10–20km, the proportion of patients who had been in inpatient care for more than a year increased as the distance increased.

Those further from home tend to be younger (under 18). The percentage of people 100km or more from home for those under 18 was 42% compared to 19% for the whole population.

How long are people in inpatient care for?

Total 1190 patients (40%) had a length of stay up to 1 year; 1300 patients (43%) had a length of stay between 1 and 5 years; 510 patients (17%) had a length of stay of 5 years of more; 1620 patients had received continuous inpatient care between the 2014 and 2015 census collections. Of the 3000 people receiving inpatient care on census day 2015, 1,450 patients (48%) were receiving care at the time of all 3 censuses.

Length of stay by ward security level

The proportion of patients with a length of stay of over 1 year is higher in secure wards. Total 48% (750 patients) on a general ward, 77% (620 patients) on a low secure ward, 72% (375 patients) on a medium secure ward and 91% (60 patients) on a high secure ward had a length of stay of more than 1 year. Of those in a high secure ward, 59% (40 patients) had been in these settings for 5 years or more.

Care plan

All patients had a care plan. Total 805 patients (27%) were reported to have a care plan record of ‘working towards discharge’ while 145 patients (5%) were recorded as having a delayed transfer due to placement unavailability. This leaves a total 2050 patients (68%) whose care plan status identifies that the patient needs to remain in inpatient care.

Discharge rate

The average ‘approximate rate of discharge’ for England was 39%, indicating that following the census collection in 2014 39% of inpatients were discharged and not receiving inpatient care on census day 2015.

Delayed discharge

When looking at each care plan, 145 patients (5%) are recorded as having a delayed transfer due to placement unavailability. If we are more specific about the reason for delayed discharge, the top reasons include: 41% of delays were attributed to waiting for residential home availability; 20% of delays were attributed to waiting for further non-acute NHS care; 14% of delays were attributed to waiting for completion of assessment; 8% of delays were attributed to waiting for public funding.

If we consider just young people under 18 (165, 6%), 4% were recorded as having a delayed discharge due to placement unavailability.

In December 2016, NHS Digital started to report new data related to out-of-area placements (OAPs). The latest data (NHS Digital January 2017) shows that at the end of November 2016 there were 528 OAPs active, of which 95% were due to unavailability of a local bed (an inappropriate OAP). This only includes OAPs that started on or after 17 October 2016.

Which organisation type was the delay was attributed to?

In 32% of cases the delays were primarily attributed to healthcare delays by the NHS, in 34% of cases the delays were primarily attributed to social care and in 23% of cases both agencies were considered to share the responsibility.

Comparison with Assuring Transformation

Linking the 2 collections at patient level, 2140 patients were common to both collections; 855 patients who appeared in the Learning Disability Census did not appear in the Assuring Transformation collection; while 480 patients from the Assuring Transformation collection did not appear in the Learning Disability Census. Adding the unreported patients as identified by Assuring Transformation to the 2015 headcount puts the figure who were inpatient on census day 2015 closer to 3480.

Considerations

The HSCIC has good processes in place to help ensure the accuracy and validity of its data collection methods and all data in the reference data tables were independently checked. Data was collected via the clinical audit platform (CAP) which allows a number of validations to be built in. Data was also sent to the HSCIC Personal Demographics Service (PDS) for NHS number verification and to trace a last known postcode of residence where that supplied by providers was invalid or unknown. Tracing improved the accuracy of the data, for example, it increased the number of valid postcodes from 2180 records (73%) to 2980 records (99%), which was important for recording accurately how far someone receiving care was from home.

The data collected was also in line with previous years. The 2013 and 2014 censuses reported 3250 and 3230 patients in scope respectively which adds confidence to the figures. It is worth remembering that the Learning Disability Census collections are just a snapshot in time and fluctuations between the collections cannot be seen here.

Despite the efforts of the HSCIC to report accurately on the number of people in our population receiving inpatient treatment, when the data is compared to a similar data collection from Assuring Transformation a number of differences appear that highlight that there are patients unreported in both collections and that the overall figure for the number of inpatients on 30 September 2015 is closer to 3480.

The Assuring Transformation collection is a commissioner-based collection. Data are provided by English commissioners, whereas the Learning Disability Census is based on a provider collection. There is also a slight difference in scope between the 2 collections. The census comprises data from providers based only in England, but does include care provided in England but commissioned from other UK countries. Assuring Transformation includes care commissioned in England and provided elsewhere in the UK. In total there were 50 patients who received care outside of England who were included in the Assuring Transformation collection but who would not be expected to appear in the census. There were also 80 patients who were commissioned outside England who therefore would not be expected to appear in the Assuring Transformation data set. This difference in scope means that some patients would not be expected to link to the other collection.

From January 2015, responsibility for the Assuring Transformation data collection and publication were transferred to the HSCIC. This addressed key requirements around the improvement of data quality and reporting frequency.

These figures show that there is still work to be done in terms of obtaining full coverage of inpatients with learning disabilities and/or autism. The Learning Disability Census is not likely to take place again, but it is expected that comparable data will come from the Mental Health Services Data Set (MHSDS). However, the

Assuring Transformation collection will continue to be collected by HSCIC in its current form for some time.

Additional paper referred to

NHS Digital (Jan 2017) ‘Out of area placements in mental health services: November 2016’. In December 2016, NHS Digital started to report new data related to OAPs. In January 2017, the first full monthly figures were published. The OAPs collection is a new data collection, and difficulties in completeness and accuracy are to be expected as with any new collection. It should also be noted that these figures are based on OAPs that have started since the beginning of the collection, that is, 17 October 2016. Therefore, the report is only based on new placements as of this date.

Knapp M, Comas-Herrera A, Astin J, Beecham J, Pendaries C. (2005) Intellectual disability, challenging behaviour and cost in care accommodation: What are the links?

Review question(s): 2.1, 4 (economic narrative summary)

Organization the authors were involved with:

1. Personal Social Services Research Unit, LSE Health and Social Care

2. Personal Social Services Research Unit, University of Kent

3. West Kent NHS and Social Care

4. Centre for the Economics of Mental Health, Institute of Psychiatry, King’s College, London

Type of study: Cross-sectional

Country: UK

Population: Adults with learning disabilities and behaviour that challenges, living in care accommodation in some areas of England. The sample in the study is 930 people.

Type of service: accommodation, general hospital services, day activity services and primary care and community support

Quality score: +

Study aim

To understand the pattern of costs and service use among individuals with intellectual disabilities in residential care, to understand the factors that contribute to variation in costs, including individual characteristics like level of intellectual disability and challenging behaviour, and to identify the unit costs of services received. p298

Methods

Data were collected in 1996 from various parts of England - only individuals with cost information were included in this analysis. Costs were collected using the Client Service Receipt Inventory.

Characteristics

For the costed sample of 930 people, the mean age of service users was 44.4, range 20-92. The level of Intellectual disability was mean 21.9, range 0-42 measured on the Learning Disability Casemix Scale (LDCS). The level of challenging 7.5 mean 0-30 range measured using the same scale.

Findings

Patterns of service use

The use of services outside residential care reflected the degree of intellectual disability and behaviour that challenges. There was also a sector effect, for example, service users living in NHS settings were more likely to use NHS day hospital services, see a dietician or occupational therapist, but less likely to go to an education centre, drop-in centre of other social club, and also less likely to see a GP.

The utilisation rate of services was as follows:

Hospital

- General hospital outpatient 10.4%
- General hospital accident & emergency 7.3%

Day activity services

- Intellectual disability hospital-based day activity 17.2%
- Work-orientated centre 11.1%
- Day centre or social club (non-NHS) 39.3%
- Education centre 16.9%
- Drop-in centres 15.4%
- Other day care 29.8%

Primary care and community support

- General practitioner 55.7%
- Dietician 25.2%
- Speech therapist 20.5%
- Occupational therapist 22.4%
- Psychologist 12.2%
- Psychiatrist 20.1%

Hospital-based day activity made the largest contribution to total cost, reflecting both an intensive use as well as a higher unit cost than the other types of day services. Day centres and social clubs were the more widely used day services.

What influences service use?

A number of different factors were found to influence service use including:

Level of intellectual disability
The degree of intellectual disability influenced the use of all services. Individuals with more severe intellectual disabilities were more likely to use services such as speech therapy, physiotherapy or hospital based day activities. Non hospital-based day activities tended to be used by people with more moderate intellectual disabilities.

Extent of challenging behaviour

The extent of challenging behaviour influenced used of: day centres/social clubs, psychologists, psychiatrists and dieticians

Age
Other characteristics, such as age, affected the probability of receiving services. Older people were less likely to be offered services such as places at work-oriented centres, or seeing a psychologist or a speech therapist, but more likely to see a GP (p301).

Size of residential home
People in smaller homes were less likely to go to work centres, education centres or drop-in centres, but on the other hand were more likely to go to day centres. p302

Sector
People living in private/voluntary homes were less likely than people in NHS facilities to use hospital-based day activities, but more likely to go to education centres or drop-in centres, or receive other types of day care. They were also more likely to see a GP, but less likely to see an occupational therapist or dietician. p302

Whereas NHS trusts tended to specialise in providing services for people with more severe level of disability. The mean score on intellectual disability of people living in an NHS home was 25.6 compared with 13.5 for private or voluntary sector. The mean score on challenging behaviour of people living in an NHS home was 8.9 compared with 5.8 for private or voluntary sector.

Cost information

In the costed sample, accommodation was provided by:

- Seven NHS Trusts (66% of people in the sample)
- Six private for profit providers (25% of the sample)
- One voluntary or non-profit provider (9% of sample)

The average weekly cost for sample members (£, 1996/97 prices) was £692, which includes averages of: £588 accommodation (and associated staffing); £75 day care; £22 professional or community services; £7 acute healthcare.

Average costs were higher in NHS settings where residents scored more highly on both the intellectual disability and challenging behaviour indicators, which may partly explain the higher costs.

In terms of scale of facility, NHS facilities benefited from economies of scale with cost being just under £2 lower per resident week for each additional resident in the facility. Whereas in the voluntary/private facilities there was 'diseconomies of scale', with each additional resident in the home generating an additional cost of £2.48 per resident week across all residents. p303

Implementation issues

In the context of a national policy commitment to person-centred planning, the study suggest that commissioners need to explore the sources of cost variation between individuals, sectors and types of accommodation in order to meet the policy objectives on quality, choice, independence and inclusion.

Things to think about

The sample of people with intellectual disabilities was non-randomly selected and over represented the NHS sector and under-represented the other sectors which makes it difficult to generalise the findings nationally.

You also need to be cautious in drawing conclusions from the cost data. First, the data in the study is from a relatively small number of independent providers. Second, aggregated cost for residential accommodation settings were used and we don't know the extent of which if any service costs might have been included in the accommodation cost so this means the analysis relates only to services not already provided within the accommodation budget. Third, there was a lot of variance in costs which the authors cannot fully explain, however they say 'many other cost studies in the intellectual disability field have attained very similar proportions of variance' (p304).

Local Government Association (2016) Learning disability services efficiency project

Review question(s): 2.1 (economic narrative summary)

Type of study: report based on case studies

Country: England

Population: adults with learning disabilities

Quality score: -

Aims

The Local Government (2016) report shares the findings of five councils (London Borough of Barking and Dagenham, Darlington Borough Council, Cumbria County Council, Kent County Council and Wiltshire Council) in their attempt to develop cost-effective services for adults with learning disabilities. Their findings are based on results over a two-year period (p.4).

Methods

This report discusses case studies from 5 councils to illustrate how cost-effective services are being developed (p.4).

Findings

We report on the findings that include an economic aspect. The report describes other examples of innovative services without mentioning impact on costs. For further detail, refer to the full report.

Kent County Council’s “Kent Pathways Model” supported 166 individuals with moderate learning disabilities with the aim of increasing their independence. The program has led to an estimated cashable savings of £35/week whilst achieving “more independent outcomes” for the two-year period from 2015/16 and 2016/17 (p.9).

- It is not reported whether individuals have challenging behaviour.
- The costs of setting up and operating the service are not reported, nor are the methods of calculating costs or outcomes.
- This is not an economic evaluation and further research is needed before confidence can be placed in the findings.

Cumbria developed a new service targeting individuals who might ordinarily be placed out-of-area due to their more complex needs. The service provides support to four individuals living in their own apartments on a single site and staff can respond to crisis when needed. A case study is provided on an individual named, ‘R’, who has moderate learning disabilities and autistic traits, and whose placement had broken down. ‘R’ was moved into the new support service with the goal of increasing independence and reducing direct support hours. Since starting the support, costs have fallen from £3,422 per week to £2,0003 per week and it is thought ‘R’ has the potential to progress even further in independence (p.13).

- It is not reported whether this individual has challenging behaviour.
- The time period of the change in costs is not reported.

Cumbria Council also developed a step-down service targeting individuals with complex needs, coming from hospital or forensic services. The step-down service provides residential accommodation with nursing. A case study is provided on an individual named, ‘D’, whose care package costs are £2,318/week in the community, compared to £2,633/week for hospital services. This savings of £315/week in care package costs equates to £11,199/year in 2015/16 (p.13). Savings for 2016-17 are reported to be £16,417 (p.13). This individual had formerly spent 17 years through 4 admissions to either inpatient or secure services (p.13).

Kent Council increased is promotion of the Shared Lives program to attract hosts for people with learning disabilities or autism, long-term mental ill health, or dementia (p.21). The renewed efforts came with an increase of 29 placements. They report a savings of £430,000 due to these new placement arrangements.

- The proportion of individual with challenging behaviour that were placed and the proportion of savings as a result of hosting these individuals are not reported.

Cumbria Council undertook a redesign of services for individuals living in a 5-bed residential care setting that had 1 waking and 2 sleeping nights (p.23). The review determined that waking night support was no longer necessary and redesigned the service, which involved purchasing a new building to provide 4 self-contained flats with shared support. It is estimated that this redesign will save £225,000/year and increase individuals’ independence.

- The proportion of individual with challenging behaviour that were placed and the proportion of savings as a result of hosting these individuals are not reported.

The Local Government report also lists the gross expenditure on learning disability services across the 5 councils from 2013/14 to 2016/17 and provides information on cost-savings made (p.24).

Economic considerations

These case studies are limited in that they have not reported the:

- Costs of setting up and operating the service
- The methods of calculating costs-savings and outcomes
- Which outcomes were measured and with which instruments

These case studies are not economic evaluations and further research is needed before confidence can be placed in the findings.

Limitations of the study

This report provides a summary of findings across the 5 councils aiming to provide more cost-effective services in a time of budgetary pressures.

However, this summary report is not high quality as information on methods, data collection, selection of case studies, and analyses are provided in very little detail, making it difficult to verify the reliability or validity of the findings.

This report is useful in illustrating various approaches to redesigning more cost-effective services, but due to limited reporting, the impact on costs and outcomes is not clear and robust research and reporting is required.

Mansell J, Ritchie F, Dyer R (2010) Health service inpatient units for people with intellectual disabilities and challenging behaviour or mental health problems

Review question(s): 2.2

Organisations the authors were involved with:

1. Tizard Centre, University of Kent and Canterbury
2. Healthcare Commission, London

Type of study: Cross-sectional survey

Country: UK

Population: respondents to the survey were from every NHS unit and every independent healthcare (IH) (private or voluntary) service registered in England providing inpatient services for people with intellectual disabilities that identify themselves as assessment and treatment units, low secure or medium secure units

Quality score: +

Type of service: Inpatient services

Aim of study: From a national survey of health service inpatient units for people with intellectual disabilities, this study aims to describe the characteristics of the services studied in the audit and to compare the different types of service (assessment and treatment units, low secure and medium secure units); it also compares NHS and IH units

Types of services: In total, services provided 1891 places, 1492 places in NHS providers and 399 in independent health providers

Findings

The geographical spread of services was very uneven. Among those areas with services, the average number of places was 6.04 per 100,000 total population, but there was very wide variation from 1.75 to 24.19 places per 100,000 (p554).

Differences between NHS and IH providers

The assessment and treatment centres that were provided by IH providers were larger compared to NHS providers and they were more likely to be fully occupied compared to NHS units. There were no significant differences in numbers of places between the 2 providers when it came to the low and medium secure units.

Independent assessment and treatment units had lower staff/patient ratios (2.1:1 vs. 3.8:1) and made less use of agency staff (3% vs. 42%) than NHS assessment and treatment units, but in NHS medium secure units the NHS providers used less agency staff compared to independent providers.

IH providers' low secure units had more referrals to social services departments for adult protection issues than NHS low secure units.

NHS units had more patients who had finished active treatment but did not have any plans to leave the service in the next month compared to IH units, and assessment and treatment units had a higher proportion of such patients (at 25%) than low (10%) or medium (3%) secure units. None of the IH providers said they had people who had finished treatment but were without plans to leave in the next month.

Differences between types of unit

A large proportion of people in assessment and treatment units and low secure units did not have a care plan (55%, 44%) – this compares to only 14% in medium secure units who did not have a care plan. Assessment and treatment units and low secure units had more visitors than medium secure units. Assessment and treatment units had more incidents and incidents of injury to staff than low secure units, but medium secure units had more incidents for people who lived there than low secure units.

Considerations

There were far fewer surveys returned from IH providers compared to NHS providers, with the lowest returns of surveys from independent assessment and treatment units (only 46% compared to 97% NHS providers). The authors say that the respondents from the pilot surveys were not asked to fill in the questionnaire again, and this led to an under-representation of the IH assessment and treatment unit returns. The low returns from this sector and type of unit may affect what we can know about the characteristics of IH providers who provide this kind of unit.

There was no information collected about the nature and severity of learning disability and behaviour that challenges, so some differences, particularly between types of units, may be due to the different characteristics and service needs. In addition, a difference in the number of incidents may reflect the better abilities of staff to recognise and record incidents.

McBrien J, Gregory J, Hodgetts A (2003) Offending and risky behaviour in community services for people with intellectual disabilities in one local authority

Review question(s): 2.1

Organisations the authors were involved with:
1. Learning Disability Service, Plymouth Primary Care Trust
2. Peninsula Medical School, University of Plymouth

Type of study: A cross-sectional survey in 1 local authority

Country: UK

Population: Adults with learning disabilities in 1 local authority area

Type of service: Residential services, day services and respite units

Quality score: +

Study aim

To survey the total population of adults with intellectual disabilities known to health and social services living in, or originating from, 1 local authority area to establish the extent of offending and risky behaviour. The results were intended to form a basis for service development.

Findings

Baseline data

The prevalence of adults with intellectual disabilities (ID), in 1 local authority area, known to health and social care services, is 0.68%. This is much lower than the Department of Health estimate of 2%.

The prevalence of adults with ID who had offended or were at risk of offending (by virtue of their behaviour) was 26% of the total people with ID (1326)

This finding suggests that adults with ID who had offended or were at risk of offending is a sizeable group, whose needs need to be identified and services organised accordingly.

Common experience for local providers to have had experienced caring for clients with a history of criminal justice system (CJS) contact, suggesting that training staff in forensic ID is important.

Characteristics

The majority (63%) of people in this study had had no contact with the CJS although demonstrating risky behaviour; 37% of people had had contact at some point in their lives – a prevalence of 9.7% of those known to services. In terms of the settings, 48% had clients with a history of contact with the CJS and 93% of the care managers reported clients on their current caseloads who had had such contact.

Behaviour characteristics

The most frequent behaviours displayed in the settings were: attacking others 63%; throwing temper tantrums in public places 55%, making sexual approaches to adults 51%; and showing offensive social behaviour in public 42%. Care managers experienced high rates of these behaviours among clients on their current caseloads.

In terms of behaviour displayed by individuals, ‘social’ behaviours such as showing offensive social behaviour in public and throwing temper tantrums in public places were most common (53%), followed by assault-related 47%; sex-related 41%; and property-related 36%.

Of the 84 settings: 26% said all clients were there by virtue of having challenging behaviour; 35% said some were; 39% said none were. A total of 5% of settings said 1 or more clients had been temporarily excluded for behaviour problems and 43% had excluded people permanently.

Setting and service needs

Most settings (90%) catered solely for people with intellectual disabilities; 9% of people were living out-of-area and only 3% in secure accommodation.

The number of settings that had had 1 or more clients currently sectioned under the Mental Health Act was small at 2%, while 21% had 1 or more clients previously sectioned. However, 13% of settings could not answer the question on past sections. Of the 30 people in the care manager group, 40% had clients currently sectioned.

Private homes, particularly residential, were more likely to have experience of caring for clients with a history of Mental Health Act sectioning and also had more experience of client arrests than the other sectors.

Most settings catered for a mix of men and women (62%). About a third were for men only (35%) and 3 were for women only (4%).

Considerations

The prevalence of ID in the adult population was low in the study compared to other studies. This is because it counted people in contact with health and social care services and it may have missed people not using services.

The study also relied on the views of staff and did not involve clients. As staff were asked about a person's 'risk of offending', there is the possibility that different staff might view 'risk' differently. However, many names were reported by more than 1 person so the authors were able to cross-check information about individuals to help identify any inconsistencies. The authors were not able to get all the data they wanted, especially about whether or not people had ever been sectioned under the Mental Health Act or the nature of previous offences. There is a possibility that some people with forensic backgrounds living in local settings may therefore have been missed, although anyone with currently risky behaviour is likely to have been reported on.

The study suggests that it a common experience for local providers to have had experience caring for people with a history of CJS contact. This suggests that training staff in forensic ID is important. Some 88% of those with CJS contact were living locally and might expect local provision. It is worth noting that this study was intended only to establish basic information on the extent of offending and risky behaviour. It did not include demographic information and did not seek to find out the reasons for risky behaviour.

National Audit Office (2015) Care services for people with learning disabilities and challenging behaviour

Review question(s): 2.1

Type of study: Mixed-methods – audit of progress against the Transforming Care commitments.

Country: UK

Population: People with learning disabilities and behaviour that challenges in the UK – the study looks at the cohort of 2600 inpatients with learning disabilities still living in hospitals in September 2014

Type of service: Inpatient, residential placement, community support and learning disability intensive support team

Quality score: -

Study aim

To examine the challenge the government faced and the performance against the commitments in 'Transforming Care: A national response to Winterbourne View Hospital' and the accompanying DH 'Winterbourne view review – concordat: programme of action (the concordat)' (2012). The study also identifies barriers to Transforming Care services.

How the audit was carried out
The authors used a number of different methods to collect data about how services have been performing since the Winterbourne View commitments were published in December 2012. This included:

- analysis of data collected quarterly under 'Assuring Transformation'
- review of patient case files in 4 large mental health hospitals
- review of Learning Disabilities Programme board's self-assessment returns showing progress against each of the commitments
- focus groups with clinicians, nursing staff, senior managers, directors and board members at 4 large NHS and independent mental health hospitals

- focus groups with people with learning disabilities in the community
- stakeholders' focus group and consultation in London with 9 different stakeholders
- one-to-one interviews with officials in audited bodies.

Findings

The main finding from the audit is that the government did not achieve the central goal of moving all people, where appropriate, out of hospitals by 1 June 2014 because 'no mechanisms existed for the systematic pooling of resources to build sufficient capacity in the community to enable it to happen' (p38).

Characteristics

Cohort of people with learning disabilities still living in mental health hospitals in September 2014.

Length of inpatient stay

The average length of continuous inpatient stay (including transfers between hospitals) in the 4 hospitals visited in the study was 6 years and 4 months. The average length of stay, including admissions and readmissions, in the 4 hospitals visited in the study was 17 years and 4 months.

Legal status

In September 2014, of the 2600 people in mental health hospitals, 83% had been sectioned under the Mental Health Act, with 46% receiving a civil section and 37% receiving a criminal section. A further 11% were admitted under normal referral procedures, and 5% fell into various 'other' categories for placement in a mental health hospital.

Costs

The 2013 published Learning Disability Census data was used to estimate the cost of treating people in inpatient hospital services. In 2012–13, the NHS spent £557 million on this care for people with learning disabilities within the 58 NHS and 49 independent hospitals, with assessment and treatment centres. In addition, in 2013–14, local authorities spent £5.3 billion on services for all adults with learning disabilities. However, we don’t know how much of this was spent just on services for people with a learning disability and challenging behaviour which is a much smaller group.

What gets in the way?

As part of the audit, the authors have identified some of the things that are getting in the way of services being able to develop local community services capacity. These include the following.

Poor quality of information

The poor quality of data on patients with learning disabilities and challenging behaviour makes it difficult to identify good practice and to have accurate information to help develop appropriate community capacity.

Delayed discharge

As at September 2014, 92 inpatients did not have a transfer date because of a lack of suitable housing provision. The clinicians that took part in the study said that delays in discharging people were often because of: ‘delays in funding decisions; a lack of suitable accommodation; and insufficient capacity and capability among community providers to provide the required care package’ (p35).

Out-of-area placement

Total 36.7% of patients were admitted to hospitals over 50km from their home area (HSCIC Learning Disabilities Census Report – England, September 2013).

NHS–local authority interface

In June 2013, only 27% of local authorities had pooled budgets and 20% had other risk-sharing agreements despite this being a key government commitment.

What helps services to improve the capacity and quality of local services?

As part of the audit, the authors have identified some examples of good practice on things services are doing to improve capacity and the quality of local services. Most of the examples of good practice come from the Salford local authority and clinical commissioning group.

Joined-up health and social care

In Salford, they have implemented a joined-up health and social care management and commissioning structure with a pooled budget. However, this has taken over a decade to introduce.

Monitoring outcomes

The clinical commissioning groups and local area interviews as part of the audit emphasised that holding providers to account is essential in ensuring that the person has a sustained and successful community placement (p36).

Placement support

In Salford, the commissioners are co-located with a multidisciplinary specialist learning disability community team that can work with providers at short notice to maintain placements, when a service user's behaviour might otherwise lead to hospital admission or readmission.

Proactive support

In Salford, people with learning disabilities are supported to communicate their views and reduce challenging behaviour, through accessing mainstream leisure, health and social services, but are still supported by the multidisciplinary team.

Ways of working

Salford has developed a holistic community-based model of support. The service user is at the centre of their delivery model and they have developed a culture based upon mutual support and commitment to giving people meaningful lives, rather than just getting them out of hospital.

Considerations

Overall the quality of the audit is limited. However, the authors have made efforts to seek the views of different stakeholders including service users and carers and to see the issue from different viewpoints. Yet, it is difficult to ascertain in the report how strong different themes were or who the views belonged to. The barriers and facilitators section of the report is limited and the conclusion doesn't always match the findings. For example, 1 of the main conclusions of the audit is that 1 of the key challenges in improving care is to 'to determine the most appropriate place for people's assessment and treatment' (p38) yet this isn't a finding discussed elsewhere in the report.

While the report points to some of the things that are getting in way of transforming services and these seem valid for the examples of good practice provided, we don't know if they are effective. We haven't been able to find any other published evaluations about how Salford is transforming services to know if what they have put in place is still in place or is effective.

National Audit Office (2017) Local support for people with a learning disability

Review question(s): 2.1, 5.2

Type of study: Mixed-methods audit of progress against the Transforming Care commitments

Country: UK

Population: People with learning disabilities and behaviour that challenges in the UK – the study looks at the cohort of 2510 inpatients with learning disabilities still living in hospitals in December 2016

Type of service: Inpatient, residential placement, community support and learning disability intensive support team

Quality score: -

Study aim

To look at how much the government spends on supporting people with a learning disability and to find out if support is improving outcomes for this group. The study also examines the progress the government has made with its transforming care programme to provide community services and reduce mental health hospital beds for people with a learning disability. The study also identifies barriers to transforming care services.

How the audit was carried out

The authors used a number of different methods to collect data about how services have been performing since the Winterbourne View commitments were published in December 2012. These included the following.

One-to-one interviews with officials in audited bodies

Six case study visits to local authorities and clinical commissioning groups. This included one-to-one interviews with officials and interviews and focus groups with carers and people with a learning disability at each of the 6 case study sites.

Focus groups with families and people with a learning disability and behaviour that challenges services as part of an event discussing the Transforming Care programme.

One-to-one interviews with representatives from the National Valuing Families Forum and the Challenging Behaviour Foundation.

A panel of experts including providers, charities and academics and held a panel discussion with providers from Care England.

Clinical commissioning groups were surveyed about joint financial arrangements and joint working.

Key documents were reviewed and analysis of data collected under Assuring Transformation.

Findings

The main finding from the audit is that the Transforming Care programme is making progress in reducing the number of people in mental health hospitals, but the programme partners consider it likely that the programme will not deliver the 35 to 50% reduction in bed numbers by 2019.

There has been little progress in achieving the other main objectives of the programme which are that patients in mental health hospitals are closer to home and that that the length of time people stay in mental health hospitals reduces.

We have not extracted the data in the study that relates to supporting the wider learning disability population because we don't know how much of it would relate to our narrower population of people with learning disabilities and behaviour that challenges services.

Characteristics

Cohort of people with learning disabilities still living in mental health hospitals in December 2016.

Age
Under 18 n=160 (6%)
19–65 n=2305 (92%)
Over 65 n=45 (2%)

Types of mental health hospitals
Of the 2510 people with a learning disability and/or autism in an inpatient setting in December 2016, they were located in:
Non-secure: n=1235 (49%)
Low secure: n=735 (29%)
Medium secure: n=475 (19%)
High secure: n=65 (3%)
Non-secure covers a range of inpatient beds including specialist learning disability units, generic mental health, rehabilitation beds and psychiatric intensive care units.

Length of inpatient stay

In December 2016, the average length of stay in a mental health hospital for a person with a learning disability was 5.47 years. The average length of stay has continued to increase since March 2015, when it was 5.09 years. This data is only for people who are still in hospital and does not include people who have been discharged. The number of people who were in hospital for more than 5 years reduced from 930 people in March 2015 to 890 people in December 2016. This means that people discharged had lower than average lengths of stay.

Distance from home

In November 2016, 20% of people in mental health hospitals were 10km or less from home and 46% were 50km or more from home. The distance from home remains unchanged from what it was in December 2015.

Legal status

In December 2016, 24% of people in mental health hospitals overall were under restrictions by the Ministry of Justice and therefore not free to leave.

Destination after leaving mental health hospitals

Between October 2015 and September 2016, 33% of people discharged from mental health hospitals went into residential care, 31% went into supported housing and 26% into the family home with support.

However, for the cohort of all people with a learning disability, and not just those leaving hospital, the proportion of people living in the community with family or with their own tenancy has increased from 70% in 2011–12 to 75% in 2015–16.

Costs: providing support in mental health hospitals.
It costs £3,500 per week (£180,000 per year) to support the majority of people with a learning disability in secure and non-secure mental health hospitals. (NHS Digital Data from September 2015 was used for this analysis).

What gets in the way?

As part of the audit, the authors have identified some of the things that are getting in the way of services being able to develop local community services capacity. These include the following.

Risk registers

Data in risk registers is particularly poor on people in the criminal justice system and on children about to enter the adult system so they are not identifying all people at risk or waiting to be admitted to mental health hospitals.

Care and treatment reviews not taking place

Care and treatment reviews became mandatory in October 2015. Without them, the process of discharging people and getting them appropriate support in the community cannot work to best effect. In December 2016 63% of people admitted that month did not have a pre- or post-admission review, 28% had never had a review and 39% of people had had a review in the past 6 months.

No single point of contact

Some of the families and patients consulted as part of the audit said that while care and treatment reviews were a good starting point, ‘without a single point of contact to effect change and coordinate resources, families found the process of discharge from mental health hospitals to be incomprehensible and emotionally draining’ (p35).

NHS–local authority interface

As of summer 2016, only a third of clinical commissioning groups had pooled their budgets with individual local authorities (taken from a survey of clinical commissioning groups). The other main funding mechanism to help transfer money from mental health hospitals to community support is ‘dowry payments’. These are for people who have been in mental health hospitals for more than 5 years. There are 900 patients potentially covered by dowry payments. The audit found that these had not been working as intended: ‘Although 105 people eligible for these payments were discharged between April 2016 and December 2016, there is poor understanding about how these payments will work in practice’ (p39).

Considerations

Overall the quality of the audit is limited. However, the authors have made efforts to seek the views of different stakeholders, including service users and carers and to see the issue from different viewpoints. Yet, it is difficult to ascertain in the report how strong different themes were or who the views belonged to.

While the report points to some of the things that are getting in way of transforming services and these seem valid, we don't know if implementing them would be effective.

Oxley C, Sathanandan S, Gazizova D, Fitzgerald B, Puri BK (2013) A comparative review of admissions to an intellectual disability inpatient service over a 10 year period

Review question(s): 2.2

Organisations authors were involved with:
1. Central & North West London NHS Foundation Trust.
2. Hammersmith Hospital and Imperial College London. Department: The Seacole Centre

Type of study: Retrospective review of hospital records

Country: UK

Population: People with intellectual disabilities with acute mental illness and/or challenging behaviour

Quality score: -

Type of service: An intellectual disability unit

Aim of study: This study looks at trends in admissions to an intellectual disability unit over a 10-year period – it compares trends in admissions between the time periods of 1999–2001 and 2009–13

Findings

Discharge destination

Most patients in the 1999–2001 study were discharged to either the same residential home or back to the family home, whereas in 2003–11 patients were most frequently discharged to either a different residential home or to supported living. The authors say that this may be because people are being discharged to places more suited to meet their needs.

Reason for admission

The most frequent reason for admission is challenging behaviour (62% in 1999-–2001 and 63% in 2009–11), followed by psychosis (22% in 1999–2001 and 11% in 2009–11).

However, ‘social admissions’ were the third most common reason. Social admissions do not have anything to do with clinical need, but with reasons like having discharges delayed because of finding funding for a suitable placement. This was the case in the first study period and also the second.

Length of stay

The average (mean) length of stay/days in 1999–2001 was 198.6 and in 2003–11 it was 244.6.

The length of stay over the 10-year period has slightly increased from an average of 198.6 days up to 244.6 days. The authors say that this shows that admissions are longer than in more generic medical settings.

Considerations

We do not know what proportion of the people admitted to the unit came from out-of-area or if they had any particular characteristics, although we know that the hospital covered 7 boroughs and are likely to include people who were admitted from outside of their local area.

It’s not possible to determine how representative the patient group is without comparisons to national data.

No statistical tests for significant differences undertaken, so it’s difficult to know whether the differences were due to chance or real.

As with other observational studies of hospital records, the reliability of the findings depends on the accuracy and extent of reporting of information at the time, which is difficult to check.

However, the study spans a long period of time in a large London borough, where demand and costs for accommodation are likely to be high. This study's findings may be generalisable to areas of the UK under similar pressures.

Pritchard A, Roy A. (2006) Reversing the export of people with learning disabilities and complex health needs

Review question(s): 2.1

Organisations authors were involved with:

1. Shropshire County PCT and Shropshire County Council
2. South Birmingham Primary Care Trust

Type of study: Cross-sectional survey with interviews

Country: UK

Population: Young people and adults with learning disabilities and complex needs in the West Midlands region of the UK – this is an area covering a population of 5.3 million and 13 commissioning authorities; 1239 people with learning disabilities and complex needs were identified in the area

Type of service: Community services for people with complex health needs

Quality score: -

Study aim: To look at the extent to which people with learning disabilities who have mental health needs, severe challenging behaviour, autism and offending behaviour originating from the West Midlands were being placed locally or out-of-area to have their support needs met.

Findings

Characteristics

The study looked at 2 groups of people with learning disabilities and complex needs. One group, the 'complex mental health needs' group, typically had a mild or moderate learning disability accompanied by offending or extremely challenging behaviour often associated with autism and mental health problems. Total 40% of people in the study were in this group. The second group, ‘severe learning disability’ had a severe learning disability and high dependency needs often associated with additional physical and behaviour problems. A total of 60% of people in the study were in this group.

Age: 72% of people were in the 19–45 age range. The majority of people (74%) placed out-of-area were in this age range. Only 17 people in the study, around 1%, were in the age range 13–18.

Gender: 77% of people in the ‘complex needs group’ were male; and in the ‘severe’ group it was 64%.

Ethnicity: there was only data collected for the ‘severe’ group. There were no big differences between the ‘in-area’ and ‘out-of-area’ groups. For the out-of-area group, 88.5% were white, 7% were black Caribbean, 3.5% were Indian and 1% were Pakistani. For this group, the range of white clients ranged from 73% in urban areas to 100% in rural areas. Conversely, black Caribbean clients ranged from 0% in a predominantly rural authority up to 27% in an inner-city authority.

How common is out-of-area placement?

For the ‘complex needs’ group 41% were placed out-of-area and for the ‘severe learning disability group’ 29% were placed out-of-area.

Are there any difference in the provider market in- and out-of-area?

Complex mental health needs group

For people who were placed out-of-area, the authorities contracted with 67 providers between them with a very high reliance (80.5%) on the private sector. Some 12% of providers were in the voluntary sector and 7.5% were NHS providers. For clients placed within area there were 42 providers of whom 45% were private, 31% were in the voluntary sector and 24% were NHS providers.

The authors say that when they looked at very complex cases, out-of-area, all placements were either in a hospital, nursing, or residential home and none were in a supported living service.

Severe learning disability group

There was a higher reliance on the private sector for the out of area placements than for local placements (68.5% and 45% respectively) and a lower reliance on the voluntary sector (19% and 43% respectively). Over 80% of the placements in- and out-of-area were residential homes.

Costs

The costs in the study were based on 2002–3 prices. Out-of-area placements were more expensive. For all people the average cost of an out-of-area placement was £72,259 and for a local placement £54,112.

Complex needs group

The average cost of a care package in this group was £84,433. Of this, the average cost for an out-of-area placement was £97,509 and the average cost of local placement was £74,767. Over 80% of this client group needed packages costing in excess of £60,000 per year. In the most expensive range (over £90,000 per year) 33.5% were placed out-of-area compared with 19.5% of those placed locally.

Severe learning disability group

The average cost of a care package in this group was £43,829. Of this, the average cost for an out-of-area placement was £46,524 and average cost of local placement was £42,829. There were no differences in the proportion of clients placed out-of-area and locally for any of the cost bands. Similar proportions were spent out of area compared with local placements.

What's getting in the way?

The commissioners said there were a lot of things getting in the way of being able to provide services locally. These include the following.

Capacity issues

Blocked inpatient beds due to lack of community placements. Local services unresponsive to new crises, leading to out-of-area placements, often in the private sector. Severe shortage of local forensic beds.

Choice and control

Lack of choice from services and providers. Lack of control over cost of placement.

Resources

Difficulties in completing resettlement. Difficulties in disposing of surplus land and developing sites. Difficulties in managing transitional costs (double running costs).

Staff skills

Local service development is limited by the availability of skilled staff and a gap between numbers of professionals required and numbers trained.

Transition

Poor transition arrangements for children entering adult services. Lack of information on population, delaying planning. Problems in providing local adult services for children in distant placements.

Working together

Not much evidence of joint interagency commissioning. Poor coordination between mental health and learning disability services for commissioning and provision. Individual commissioning areas are small, making it difficult to develop services. Lack of clarity about funding responsibilities due to difficulties in interpreting guidance.

What would improve the capacity and quality of local services?

The findings from the study and comments from providers and commissioners during the study point to some of the things that could help improve the capacity of local services, these include the following.

Joined-up commissioning and working together

Developing a service for only a few people with complex needs is not very cost-effective for an individual authority; working together with neighbouring authorities with similar clients could lead to an affordable shared service.

Better information on individual needs

One of the benefits of the project has been to develop a database to collect information about needs and costs. Filling in the gaps and maintaining the database would enable commissioning to become less reactive and provide better information to help plan and develop future services.

Pathway approach to transition

The authors also suggest that there was strong support from commissioners to adopt a pathway approach to transition that would include clear milestones and specific roles for agencies, which would help to develop partnership working and to empower clients.

Considerations

The study was quite large and covered people living in both urban and rural areas. However, 2 of the 13 authorities didn't take part so we don't know how significant they might have been to the study. However, the researchers say the authorities not supplying data did not differ significantly from the responding authorities. As with other studies relying on administrative data, the reliability of the findings depends on the accuracy of the information that authorities provide. In this study there was a lack of information about young people, which means it's difficult for services to know their needs and to reconfigure services to meet future needs.

When looking at the needs of the 2 client groups in the study, it is worth noting that individuals were allocated to the groups based on information available in client records and individuals' support needs were not clinically validated. This means if historic diagnostic data is being relied on to help know what the future support needs are for people, this might be incorrect.

Pritchard A and Roy A (2006) Reversing the export of people with learning disabilities and complex health needs

Review question(s): 2.1 (economic narrative summary)

Organization the authors were involved with:
1. Shropshire County PCT and Shropshire County Council,
2. South Birmingham Primary Care Trust

Type of study: Cross sectional survey with interviews.

Country: UK

Population: Young People and Adults with learning disabilities and complex needs in the West Midlands region of the UK. This is an area covering a population of 5.3 million and 13 commissioning authorities. 1239 people with learning disabilities and complex needs were identified in the area.

Type of service: community services for people with complex health needs

Quality score: -

Study aim

To look at the extent to which people with learning disabilities who have mental health needs, severe challenging behaviour, autism and offending behaviour originating from the West Midlands were being placed locally or out of area to have their support needs met.

Findings

Characteristics

The study looked at 2 groups of people with learning disabilities and complex needs. One group, the 'complex mental health needs' group - typically had a mild or moderate learning disability accompanied by offending or extremely challenging behaviour often associated with autism and mental health problems. 40% of people in the study were in this group. The second group, 'Severe learning disability' - people in this group had a severe learning disability and high dependency needs often associated with additional physical and behaviour problems. 60% of people in the study were in this group.

Age: 72% of people were in the 19-45 age range. The majority of people (74%) placed out of area were in this age range. Only 17 people in the study, around 1% were in the age range 13-18.

Gender: 77% of people in the ‘complex needs group’ were male; and in the ‘severe LD group it was 64%.

Ethnicity: there was only data collected for the ‘severe LD group’. There were not any big differences between the ‘in-area’ and ‘out-of-area’ groups. For the out of area group, 88.5% were White, 7% were Black Caribbean, 3.5% were Indian and 1% were Pakistani. For this group, the range of White clients ranged from 73% in urban areas to 100% in rural areas. Conversely Black Caribbean clients ranged from 0% in a predominantly rural authority up to 27% in an inner city authority.

How common is out of area placement?

For the ‘complex needs group’ 41% were placed out of area and for the ‘severe learning disability group’ 29% were placed out of area.

Are there any difference in the provider market in and out of area?

Complex mental health needs group

For people who were placed out of area, the authorities contracted with 67 providers between them with a very high reliance (80.5%) on the private sector. 12% of providers were in the voluntary sector and 7.5% were NHS providers. For clients placed within area there were 42 providers of whom 45% were private, 31% were in the voluntary sector 24% were NHS providers.

The authors say that when they looked at very complex cases, out of area, all placements were either in a hospital, nursing, or residential home and none were in a supported living service.

Severe learning disability group

There was a higher reliance on the private sector for the out of area placements than for local placements (68.5% and 45% respectively) and a lower reliance on the voluntary sector (19% and 43% respectively). Over 80% of the placements in and out of area were residential homes.

Costs

This is not an economic evaluation but an administrative report of individuals' care package costs. This cannot tell us whether in-area or out-of-area services are cost-effective. This study cannot tell us why out-of-area placements are more costly. For example, this evaluation did not analyse the characteristics of individuals or service providers that are associated with higher-cost placements.

The costs in the study were based on 2002-3 prices. Out of area placements were more expensive. For all people the average cost of an out of area placement was £72 259 and for a local placement £54 112.

Complex needs group

The average cost of a care package in this group was £84 433. Of this, the average cost for an out of area placement £97 509 and average cost of local placement £74 767. However, it is not clear whether differences in costs are statistically significant, as this was not reported. Over 80% of this client group needed packages costing in excess of £60 000 per year. In the most expensive range (over £90 000 per year) 33.5% were placed out of area compared with 19.5% of those placed locally.

Severe learning disability group

The average cost of a care package in this group was £43 829. Of this, the average cost for an out of area placement £46 524 and average cost of local placement £42 829. There were no differences in the proportion of clients placed out of area and locally for any of the cost bands. Similar proportions were spent out of area compared with local placements.

Limitations in economic methodology

An important limitation is that the unit costs of care packages were not provided. It is not clear whether differences in costs are due to differences in prices or use of resources. An additional limitation is that costs are provided for one point in time. It would be ideal to understand whether and how care package costs change over a longer period of time.

What's getting in the way?

The commissioners said there were a lot of things getting in the way of being able to provide services locally. These include:

Capacity issues

blocked inpatient beds due to lack of community placements

local services unresponsive to new crises leading to out of area placements often in the private sector

Severe shortage of local forensic beds.

Choice and control

lack of choice from services and providers

lack of control over cost of placement

Resources

difficulties in completing resettlement

difficulties in disposing of surplus land and developing sites

difficulties in managing transitional costs (double running costs)

Staff skills

Local service development is limited by the availability of skilled staff and a gap between numbers of professionals required and numbers trained.

Transition

poor transition arrangements for children entering adult services;

lack of information on population delaying planning;

Problems in providing local adult services for children in distant placements.

Working together

Not much evidence of joint interagency commissioning;

poor coordination between mental health and learning disability services for commissioning and provision;

individual commissioning areas are small, making it difficult to develop services

Lack of clarity about funding responsibilities due to difficulties in interpreting guidance.

What would improve the capacity and quality of local services?

The findings from the study and comments from providers and commissioners during the study point to some of the things that could help improve the capacity of local services, these include:

Joined up commissioning and working together
developing a service for only a few people with complex needs is not very cost effective for an individual authority, working together with neighbouring authorities with similar clients could lead to an affordable shared service.

Better information on individual needs

One of the benefits of the project has been to develop a database to collect information about needs and costs. Filling in the gaps and maintaining the database, would enable commissioning to become less reactive and provide better information to help plan and develop future services

Pathway approach to transition
The authors also suggest that there was strong support from commissioners to adopt a pathway approach to transition that would include clear milestones and specific

roles for agencies, which would help to develop partnership working and to empower clients.

Considerations

The study was quite large and covered people living in both urban and rural areas. However, two of the 13 authorities didn’t take part so we don't know how significant they might have been to the study. However, the researchers say the authorities not supplying data did not differ significantly from the responding authorities. As with other studies relying on administrative data, the reliability of the findings depend on the accuracy of the information that authorities provide. In this study there was a lack of information about young people which means it’s difficult for services to know their needs and to reconfigure services to meet future needs.

When looking at the needs of the 2 client groups in the study, it is worth noting that individuals were allocated to the groups based on information available in client records and individuals support needs were not clinically validated. This means if historic diagnostic data is being relied on to help know what the future support needs are for people this might be incorrect.

Purandare K, Wijeratne A (2015) Reflections on the use of a specialist acute assessment and treatment unit for adults with intellectual disability

Review question(s): 2.2

Organisations authors were involved with:
1. Central and North West London NHS Foundation Trust, London, UK

Type of study: Retrospective review of hospital records

Country: UK

Population: Adults with intellectual disability, 78% of people admitted were because of behaviour that challenges

Quality score: -

Type of service: The Kingswood Centre is a 16-bed specialist acute inpatient unit (category 2), in Brent, a large borough in North West London –specialties include:

nursing, psychology, occupational therapy, physiotherapy, speech and language therapy, pharmacy, music therapy and day opportunities, in addition to psychiatry – the unit has an independent advocate available

Aim of study: The team looked at records of hospital admission between 1 January 2012 and 31 December 2013

Methods

People are admitted to the unit if they can no longer be looked after by community teams. A small but significant source of referrals is the criminal justice system. People are assessed for admission in the unit by a multidisciplinary team.

Data recorded in the hospital records were: Number of referrals, reason for referral, number of admissions, reasons for non-admission (when known), borough of origin, distance between home and hospital and length of stay.

Findings

In 2012, 23 out of 35 referrals (65%) led to an admission to the unit. In 2013 this was 29 out of 43 referrals (67%).

Over half the admissions during the study period (54%) had been first admitted to a mainstream mental health ward but then needed to be transferred to the specialist unit.

Reasons for transfer included:

the need for specialist behavioural assessment and treatment,

lack of appropriate training,

the need for environmental adaptations to suit the needs of patients with autism.

The average distance to the hospital from the borough of origin increased from 8.7 miles in 2012 to 12.3 miles in 2013 ($t=1.081475$; $p=0.146881$; not significant at $p<0.05$).

During the 2 years studied there were 2 admissions of adolescents to the unit because there was a lack of specialist inpatient provision for this age group within the region.

Considerations

The study looks at the hospital records in 1 area and relies on the accuracy and detail of reporting at the time. Demographic data were not collected at the time so it is not possible to see if there were differences for different people.

It is not able to say anything about people who were not admitted, for instance people who were admitted to mainstream services or private services in the area at the same time, so it can’t be used to work out the overall need for patient care in each community.

Differences in length of time of admission and increases in distance from home were not statistically significant, but this could be because there were not enough people to detect statistically significant differences.

Royal College of Psychiatrists (2013) People with learning disability and mental health, behavioural or forensic problems: The role of inpatient services
Review question(s): 2.1, 2.2

Type of study: Mixed methods: literature review and views of consultative group of professionals and practitioners, and people who use services and their carers

Country: UK

Population: People with learning disability and mental health, behavioural or forensic problems in inpatient settings

Quality score: -

Types of service:

Inpatient category 1: high, medium and low secure forensic beds

Inpatient category 2: acute admission beds within specialised learning disability

Inpatient category 3: acute admission beds within generic mental health settings

Inpatient category 4: forensic rehabilitation beds

Inpatient category 5: complex continuing care and rehabilitation beds

Inpatient category 6: category 6: other beds including those for specialist neuropsychiatric conditions

Study aim

There has been criticism about the inappropriate use of assessment and treatment beds, but this criticism often groups different beds together under that term that in fact have very different functions. This study aims to describe the different categories of beds using the typology of 1, 2, 3, 4 and 5 to inform the appropriate commissioning of different types of inpatient beds.

Findings

Based on the survey and consultation, the authors finds that the requirements of all categories of beds is about 6 to 7 per 100,000, which is a lot less than 13 years ago when the bed requirement was suggested to be 14–29 per 100,000 population. The authors say this reflects the improvements in community learning disability services and better working arrangements with generic mental health teams.

Current service provision

The Faculty of Psychiatry of Intellectual Disability's survey of inpatient beds found that there were 3954 beds within the 10 strategic health authority regions of England.

Across the categories this is approximately:

category 1=2393,

category 2=814,

category 3=no specific data available,

Categories 4/5=622,

Category 6=125.

These figures include all NHS and independent sector provision for forensic and non-forensic services and represent an almost 90% reduction from a high of over 33,000 NHS beds in 1987–88 (p12).

There was wide variation in the provision of the different categories of beds within the regions.

Recommendations

The college recommends that commissioning for inpatient services should include all 6 categories of beds, they should work with, and complement community teams, they should be focused on care pathways from hospital to the community and plan this from day 1, they may have to be regional (covering neighbouring health districts).

There should be discussion between patients, carers, professionals, providers and commissioners in each area about local need as part of a joint strategy in developing pathways of care for people with learning disability.

There should be a choice of non-specialist and specialist learning disability services. Non-specialist services may have been unpopular with people who use services and their families, but they can work well if they have specialist support available from community learning disability teams.

People who commission services should know about the 6 different categories of inpatient beds, as too often they are all grouped together and called ‘assessment and treatment units’, without understanding the different things that they do for different types of patient’s needs.

Considerations

The study is relevant to us because it looks at the current state of service provision and works out what future service provision is likely to be considering the evidence they found from the studies and the expert opinion of the stakeholders, that included both professionals and people who use services and their family. The aim of the study is to better understand the services as they are, rather than discover new things in research, and so is not organised in ways we might expect from a research study. These kinds of studies depend on the reliability of the authors rather than the study design, in this case there were many professionals who were involved as consultants as well as stakeholders of people who use services and their families and carers. There were illustrative case studies and testimonies from people who use the services.

The study is not clear about its methods of selecting studies for the literature review, although it appears comprehensive, including some international studies, but without systematic and transparent reporting methods of searching for studies there is always a chance that an important study might be missed or that other studies were omitted for some reason. It would be difficult to check or update the search in the future without knowing how the search was conducted. For this reason the study has been treated as a qualitative study of views and experiences and not a systematic review of the literature.

Seaward S, Rees C. (2001) Responding to people with a learning disability who offend

Review question(s): 2.1

Organisations authors were involved with:
1. Community nurse, Blaenau Gwent Community learning disabilities team
2. Lecturer at the University of Wales College of Medicine, School of Nursing and Midwifery Studies, Cardiff

Type of study: Cross-sectional survey

Country: Wales

Population: People with a learning disability who offend or are suspected of committing an offence

Quality score: -

Type of service: Services where members of staff in contact with people with learning disabilities who have or are suspected of having offended in 1 NHS trust (29 nurses, 4 psychologists and 2 psychiatrists)

Study aim

This study aims report on a small survey conducted in 1 NHS trust to establish the number of people with a learning disability known by staff to have committed, or suspected of having committed, an offence.

Characteristics

Most of the people identified in the surveys had a mild disability (69%) and none in the sample were said to have a severe disability. This is similar to other studies of people with learning disabilities that offend.

Most of the sample had lived alone (32%), then most likely with parents (26%), then residential accommodation (19%), then with carers (16%).

Findings

There were a small number of people (26%) who had offended only once, but a large number (35%) had offended many times (more than 5 times). This could mean that offending behaviour without early intervention could become a repeated pattern of behaviour.

There was a high proportion of people whose offence was a sexual offence. This includes offences the authors describe as ‘sexually-based behaviours’, and a third were serious sexual assaults. This is not to say that people who show inappropriate sexual behaviour then progress on to more serious sexual assaults, but that these types of sexual offences may need further investigation into the sociosexual developmental needs of this client group.

Only a small number of offences were referred to the criminal justice system, most were referred to a health professional. Offences referred to the criminal justice system were dealt with informally (caution 26%) or in the community (probation

16%). Only a small number led to a sentence and these were for sexual offences (2%).

From the numbers identified in the catchment area, approximately 1.24% of those with a learning disability in the trust's catchment area might have committed, or were alleged to have committed, an offence over a 2-year period. (p38). The numbers may be larger because of the tendency to keep responses to offending behaviour of people with learning disability within health system wherever possible (except for more serious sexual offences) and because the professionals involved in their care may not have been aware of suspected offences.

Considerations

Some studies rely on official records to tell them what population have been convicted of an offence. This study tried to find out the harder to find population of a group that may be suspected of having committed an offence, which is more difficult to define and relies very much on the personal knowledge and/or opinion of the learning disability teams and may have some inaccuracies. On the other hand, it may be more likely to capture the information of people who have not been included in official records.

Slevin E (2004) Learning disabilities: A survey of community nurses for people with prevalence of challenging behaviour and contact demands

Review question(s): 2.1

Organisation the author was involved with:

1. School of Nursing, University of Ulster, Newtownabbey, County Antrim, Northern Ireland, UK

Type of study: Cross-sectional survey

Country: UK

Population: Community nurses for people with learning disabilities in a UK region with a population of 1.68 million people – there are 8500 people with learning disabilities who are in contact with services in this area, and around 500 people remaining in hospitals awaiting resettlement

Quality score: +

Type of service: Community nurses for people with learning disabilities; this included nurses who worked in specialist challenging behaviour support teams

Study aim

The aim of the study was to answer the following questions:

What are the demographic details of the community nurses for people with learning disabilities (CNLD)?

How many clients are there on the nurses' caseloads?

How many clients on these nurses' caseloads have behaviour that challenges, and what are the contact demands of these people?

What qualifications do the nurses possess that help them work with people who have behaviour that challenges? (p573)

Characteristics or the nurses

The respondents employed as 2 team leaders (5%), 2 behavioural nurse therapists (BNT) (5%), 6 community learning disabilities sister/charge nurses (14%) and 34 community nurses for people with learning disabilities CNLD (77%). More than half were aged 32–38 (52%), 84% were employed full time, the average years of experience were 14.53 years for a qualified nurse, 12.77 years for a RNLD (learning disability nurse) and 6.48 years for a CNLD. Eleven (25%) had a degree or higher degree and 14 (25%) had a diploma.

Professional qualifications of the nurses who responded to the survey were: RNLD (registered nurse for learning disabilities) 44 (100%); CNLD (community nurse for learning disabilities) 30 (68%); RMN (registered mental health nurse) 7 (16%); RGN (registered general nurse) 15 (34%); BNT (bachelor of nursing theory) 2 (5%). The authors say that this shows that a substantial number have not received specialist education in supporting people who challenge services, even though looking after people with behaviour that challenges is a big part of their caseloads.

Findings

The survey found 550 (28%) of the people on the nurses' caseloads were reported to have behaviour that challenges, made up of 206 (32%) children and 344 (26%) adults. Of the 44 CNLD only 2 (4.5%) reported that they did not have any clients with behaviour that challenges. The median number of people on a nurse's caseload was 41.

Visits are mostly done monthly (28%) and very few people are visited less than weekly (<3%). A higher percentage of clients with behaviour that challenges are in the more frequently visited categories, but the study was not able to test this statistically. The authors point out that some people whose behaviour is not described as challenges may have complex needs that require more frequent visits too.

What works well?

Overall, 41% of the nurses said that they had taken training courses that helped them in caring for people with learning disabilities and behaviour that challenges. Different courses that were mentioned including counselling, sex education, TEACHH, reflexology, a teacher practitioner course, behaviour modification and drama therapy.

'[It] Helps me listen more to carer and client; increases my understanding of triggers for aggression, I am now better able to help parents, and I have more insight into problems' (counselling course) (p575).

'I find a lot of challenging behaviour is related to sexual problems. This course was helpful in that' (sex education course) (p575).

Considerations

The rate of return for the surveys was lower than some other survey studies of this kind (68% returned a questionnaire.) As with all surveys, the reliability of the findings depends on the questions in the survey and the representativeness of the respondents. The authors made sure that they tested the survey first to make sure that the terms used in the survey, like 'behaviour that challenges' would be understood in the same way.

The survey did not collect information about what activities the nurses did when they visited people on their caseload nor statistically test the view that people with learning disabilities and behaviour that challenges were indeed visited more often, compared to people with multiple health needs. This in practice would be quite difficult to test because people with learning disabilities and behaviour that challenges may have additional health needs too (that is, they may not be different groups that can be compared). The study does not look at the effectiveness of the teams from the perspective of nurses or families which is in another study (Slevin et al. 2007).

Unwin G, Deb S, Deb T. (2016) An exploration of costs of community-based specialist health service provision for the management of aggressive behaviour in adults with intellectual disabilities

Review question(s): 2.1 (economic narrative summary)

Organisations authors were involved with:
1. School of Psychology, University of Birmingham, UK
2. Division of Brain Sciences, Department of Medicine, Centre for Mental Health, Imperial College London, UK
3. Institute of Psychiatry, Psychology and Neuroscience, UK

Country: UK

Population: Adults with intellectual disabilities and aggressive behaviour

Quality: +

Study design: prospective observational study

Aims
This study tests whether there is a relationship between contacts with specialist community learning disability teams and individual characteristics.

Study aims

The aim of this study was to test whether there is a relationship between contacts with specialist community learning disability teams and individual characteristics.

Methods

This is a longitudinal study measuring adults' use of services at 2 time points over a 12-month period. Adults who were active users of specialist learning disability teams were recruited from 10 clinics across 6 NHS trusts in the West Midlands. Their carers (paid and unpaid) were contacted and invited to participate in the study. A total of 100 adults were recruited between 2008 and 2010. However, this study reports only on those individuals who did not have missing data. Therefore, the sample size for the analysis is n=61 adults.

As the purpose of the study was to focus on the relationship between individuals' characteristics (including aggression) and contacts with specialist learning disability services, the study only measures the use of medication and contacts with specialist community learning disability teams. Generic health services were not measured, for example, contacts with general practitioner, dentist, optician and chiropodist. Appropriate methods were used for costing, including the use of unit costs. Costs reflect the 2009/10 price year. Carers were asked to report on service use in the past 6 months, at 6 months and at 12 months.

Sample characteristics

The n=61 adults were mainly male (61.7%), mean age was 37 years (sd=14 years), most lived in community group homes (n=38, 63.3%) and the remaining with family (n=20, 33.3%). N=1 lived at a residential college and n=1 lived in their own home (p4). Half of the sample had mild–moderate learning disabilities and the other half had severe–profound learning disabilities. Most had expressive verbal communication (n=43, 71.7%), some had epilepsy (n=16, 26.7%), half had been assessed as having a mental health problem (n=29, 48.3%), and some had autism (n=16, n=26.7%) (p4).

Findings

Results – patterns of service use (costs)

A total of 90.2% of individuals (n=55) were in contact with a psychiatrist over a 12-month period, however contact with psychologists and community nurses was much lower, at 26.2% (n=16) and 24.6% (n=15), respectively. Contact with other community learning disability team specialists was also much lower, at 18% (n=11) for occupational therapists, 13.1% (n=8) for speech and language therapists, 9.8% (n=6) for physiotherapists, 4.9% (n=3) for art/drama/music therapists and 16.4% (n=10) for alternative therapists (p4, Table 1).

Average contact duration was around 30 minutes (sd=7.4) for psychiatrists, 48 minutes (sd=22.9) for psychologists, 44 minutes (sd=20) for community nurses, 55 minutes (sd=25) for occupational therapists, 63 minutes (sd=35) for speech and language therapists, 41 minutes (sd=16) for physiotherapists, 32 minutes (sd=13) for art/drama/music therapists and 38 minutes (sd=13) for alternative therapists (p4, Table 1).

The average number of contacts per healthcare professional was 3.7 (sd=4.8) for psychiatrists, 1.1 (sd=2.54) for clinical psychologists, 2.97 (sd=9.32) for community nurses, 0.79 (sd=3.24) for occupational therapists, 1.21 (sd=6.28) for speech and language therapists, 0.64 (sd=3.2) for physiotherapists, 1.44 (sd=7.28) for art/drama/music therapists and 2.54 (sd=8) for alternative therapists (p4, Table 1).

For the entire sample, mean 12-month costs per person were £419 for contacts with the community learning disability team and £369 for medications. However, these costs change depending on individual characteristics, which we describe in the next section.

Results – associations between individual characteristics and service use (costs)

Higher costs were associated with male gender (£909, sd=786) (n=37) compared to females (£594, sd=679) (n=23) (p=0.02); epilepsy (£1143, sd=779) (n=16) compared to those without epilepsy (£659, sd=716) (n=44) (p=0.03); and those who were ability to communicate verbally (£896, sd=836) (n=43) compared to those were non-verbal (£514, sd=418) (n=17) (p=0.01) (pp5, 6). These 3 factors were able to predict 23% of the variance in 12-month costs (p=0.002) (p5).

No other characteristics had a statistically significant relationship with service use/costs. However, there was a trend of higher average costs for the following characteristics: younger age, those living in family homes (vs. those in staffed community houses), those with autism and those reaching threshold for psychiatric diagnosis. Level of intellectual disability and severity of aggression had even less strong associations with service use, but there were still some levels of association between greater aggression and higher costs and mild/moderate disabilities and higher cost (pp6, 8).

Considerations

One limitation of this study is that the sample is not representative of the general population with learning disabilities and aggression (this is because individuals were recruited from psychiatrist-led clinics, which are more likely to prescribe medication and explains why contact with psychiatrists were very high).

The second limitation is the small sample size, which may bias the results in terms of costs and service use.

The authors note that few participants were in contact with other members of the community learning disability team, even though NICE guidelines advocate multidisciplinary input (p6). This is especially the case as NICE guidelines recommend that individuals be functionally assessed for creation of a behaviour support plan, which can be done by a clinical psychologist or nurse and speech and language therapists (p6). Furthermore, the authors note that aggression may be due to communication difficulties, and if this is the case, then speech and language therapist contacts may need to be higher than observed in this study (p7).

Likewise, clinical psychologist contact for this sample was low (mean=1.1, sd=2.54) even though the authors suggest that NICE guidelines encourage the input of psychologists to manage aggressive behaviour, via psychological interventions (p8).

The authors are unable to explain why male gender was associated with higher costs. Likewise, it is unclear why aggression levels did not have a significant association with service contacts.

Vaughan PJ (2003) Secure care and treatment needs of individuals with learning disability and severe challenging behaviour

Review question(s): 2.2

Organisation the author was involved with:

1. Forensic project team, The Wessex Consortium

Type of study: Cross-sectional survey

Country: UK

Population: Learning disability teams serving the populations of mid- and North Hampshire, Southampton and south west Hampshire, Isle of Wight and South East Hampshire health authorities.

Quality score: -

Type of service: Learning disability teams specialist placements

Study aim

The learning disability teams were asked to identify and complete the questionnaire for all individuals:

- who were aged 18–65 and had been identified and drawn into or may be drawn into the criminal justice system (except primarily for drugs, alcohol misuse)
- whose primary diagnosis is learning disabilities including autistic spectrum, excluding Asperger's
- whose challenging behaviour is a component of their learning disability problems (meaning threatening or dangerous behaviour to others)
- who are currently detained in conditions of security or need to be detained because of the risk they pose to themselves or others, or are likely to abscond and/ or whose self-harming or suicidal behaviour requires care in conditions of security.

Findings

What do we know about people in the study?

There were 35 individuals identified by the learning disability teams:

High secure =2,

Private secure (out of area) =19,

NHS secure (out-of-area) =6,

Private non secure (local) =1,

NHS non-secure (local) =5,

Short stay respite =1,

At home =1.

Out-of-area placements

The majority of people identified with secure care needs were placed out of their local area in private facilities, but only 3 respondents to the survey gave this as a reason for the placement being unsuitable.

Characteristics and future service needs

The majority of the individuals identified with secure care needs were subject to a civil order under the Mental Health Act. Although the majority of the challenging/offending behaviour was for violence and/or sexual offences, very few were subject to a court order. There were no differences in legal status between low secure and medium secure, which means that it probably isn’t the severity of the behaviour that challenges or offending behaviours that decides the level of security of the placement.

Women were over-represented in the group for self-harm and fire-setting. Authors suggest that there should be a consideration of this particular group’s needs when on mixed wards, because of their type of behaviour that challenges/offending behaviour needs a different type of therapeutic approach, and a consideration about their safety, because a high proportion of men on mixed wards (60% in this group) are in secure care because of sexual offences.

Considerations

The response rate was very high and is likely to be an accurate reflection of the area. It was able to capture information about both NHS and private service provision, as well as individuals who were in the criminal justice system and those who were not.

As with all surveys of this kind, the reliability of the findings is dependent on the accuracy and extent of the information requested, as well as the accuracy and extent of the information that the respondent can remember and/or know about. There could have been some individuals who had come into contact with the criminal justice system, or were at risk of doing so, that the respondents did not know about.

Wheeler JR, Holland AJ, Bambrick M, Lindsay WR, Carson D, Steptoe L, Johnston S, Taylor JL ,Middleton C, Price K, O'Brien G (2009) Community services and people with intellectual disabilities who engage in anti-social or offending behaviour: referral rates, characteristics, and pathways

Review question(s): 2.1

Organisations authors were involved with:

1. Cambridge Intellectual & Developmental Disabilities Research Group, Department of Psychiatry, University of Cambridge, Cambridge, UK

2. Psychological Therapies & Research, Northgate & Prudhoe NHS Trust & Northumbria University, Newcastle, UK

3. Psychiatry, Northgate & Prudhoe NHS Trust & Northumbria University, Newcastle, UK

4. Clinical Psychology Services, Tayside Primary Care Trust and University of Abertay, Dundee, UK

5. Department of Psychology, University of Abertay, Dundee, UK

6. Psychiatry, Nottinghamshire Healthcare NHS Trust and Rampton Hospital, Nottinghamshire, UK

Type of study: Retrospective review of case notes

Country: UK

Population: 49 people were referred due to offending behaviour which led to contact with criminal justice system (CJS) services (the CJS group) and 188 people were referred due to antisocial behaviour which did not lead to contact with CJS services (the no CJS group).

Quality score: +

Type of service: community learning disability teams (CLDTs)

Study aim

This study reports on referrals to CLDTs in 15 districts spread across 3 UK regions (covering a general population of 1.74 million), providing a picture of the operation of community ID services in relation to adults with offending or anti-social behaviour. p720

Characteristics

The average age was 36 years (ranging from 17 to 82 years). Younger age was significantly associated with being criminal justice involved (CJS), but this was due to the high age of some referrals in the non-criminal justice involved group (No CJS).

As found in other studies, people with severe learning disabilities were significantly less likely to be CJS involved than not CJS involved. The highest proportion of people CJS involved were in the mild disability group compared to other groups, but there wasn’t a significant difference within this group of being CJS involved or not.

There as an unexpectedly large proportion of the total sample who were women (41%) referred to CMLT. But there was no significant association between gender and being CJS involved.

Findings

Prevalence

The overall estimate for the prevalence of adults known to CTLD services (0.5% of the general adult population) is in line with comparable surveys of adults with ID known to UK community ID services (estimates range from 0.1% to 0.7%, e.g., Allgar et al., 2008; McBrien et al., 2003)

The current study estimates that 0.8% of the established adult ID population were referred annually as a result of behaviour which involved CJS contact.

This was similar to that found in other community surveys that found the annual incidence of offending among adults known to community ID services of between 1% and 10% (Seaward & Rees, 2001 report 1%; Lyall et al., 1995a report 2%; and McNulty et al., 1995 reporting from inner city residential services in South London, estimated 9%).

There was a difference between people referred for offending behaviour and those referred for anti-social behaviour, which was higher; Cases referred annually as a result of anti-social behaviour made up 3.8% of the established adult ID population.

Pathways into care

The majority of referrals to CTLDs came from within the community (66%) which included referrals from family, carers, general practitioners, self-referrals, and community-based health services (including referrals made by professionals within the CTLD).

A smaller proportion of referrals came to teams via social services (22%, N = 51). The least common source of referrals (12%) were via forensic and tertiary health, courts, or offender services (psychiatric inpatient, secure ID hospital, or criminal justice services).

Authors suggest that these low pattern of referrals could indicate weaker multi-agency links, or lack of effective referral systems from the CJS into the community learning disability teams. It could indicate that CJS professionals have less knowledge about some kinds of mental illness or impairment (such as borderline learning disabilities, and/ or less obvious signs of mental illness) and are then absent from this group of people with learning disabilities who are known to the community learning disability teams.

Considerations

The study was not able to get accurate figures for all of the people referred to community learning disability teams as the computer systems were not able to generate this information easily, and so prevalence data depended on what the teams knew about their clients.

The study is not able to tell us about the outcomes or quality of the services or what people thought about them as this was not information that was gathered at the time. On the other hand, the respondents to the survey came from a wide and varied geographical area covering a whole population of 1.74 million and is likely to provide a good estimate of the workloads of CNLDs in the community of people that include people who have been referred to them because of antisocial or offending behaviour, and are involved with or are at risk of criminal justice involvement.

Wong YL, Bhutia R, Tayar K et al. (2015) A five decade retrospective review of admission trends in a NHS intellectual disability hospital

Review question(s): 2.1, 2.2

Organisations authors were involved with:
1. Coventry and Warwickshire NHS Partnership Trust
2. Coventry and Warwickshire NHS Foundation

Type of study: Retrospective review of hospital records

Country: UK

Population: Adults with learning disabilities and behaviour that challenges, but not including people admitted to forensic beds

Quality score: -

Type of service: Inpatient NHS intellectual disability hospital

Study aim

This study has a similar study design to that done by Ganguly et al. (2009) which looked at admission trends to an intellectual disability hospital, but this time looked at the reasons for admissions to hospital and their nature and severity (p108) to see if there were any differences in trends after the Winterbourne View scandal.

Findings

What do we know about people admitted to hospital?

There were more people admitted to hospital in the period after the Winterbourne View scandal (2011–13) than in the period of time before; this is probably because 2 other local hospitals had closed in the local area, and that there had been a reduction in emergency respite care and day care services.

The main reason given for admission was for behavioural problems, but most people also had other additional psychiatric or medical problems.

The most common psychiatric reason given was for autistic spectrum disorders, (ASD), and this could be because professionals are getting better at diagnosing ASD. All of the people who were said to have a severe learning disability also had a diagnosis of ASD.

Out-of-area admissions

A large proportion of people who had been referred to the hospital from outside their own area had ASD (79.3%) compared to 58.6% of admissions who came from the hospital's local area. Authors say this is because there is a lack of local, specialised services for this group of people.

Over 40% of the out-of-area admissions aged 16 and younger, compared to 15.5% of admissions who came from the hospitals local area.

Length of stay

There were more admissions who stayed for a shorter amount of time (1–3 months) compared to the years before (7.8% in 2003–06 compared to 15.5% in 2011–13).

Considerations

During the study period the hospital changed status from a local tier 3 to a regional tier 4 which may have made a difference to the characteristics of the people who were admitted after the change in status. The authors point out that there was not any data on how the private and voluntary sectors who provide services may have affected the change in trends in admissions, or if reductions in admission to NHS services may have been offset by an increase in private or voluntary service provision.

There was no analysis of the data beyond reporting numbers and percentages so it’s not always possible to tell whether the differences were due to chance or were real differences.

Observational data, like this taken from hospital records, relies on the accuracy and extent of the reporting of information at the time which is difficult to check. As the authors point out, sometimes increases in trends may be due to greater understanding of a condition, like ASD, than any real increase in numbers of people with the condition.

It is often useful to compare this sort of data with national data to be sure that any differences are not due to some characteristics of that particular hospital.

Xenitidis K, Gratsa A, Bouras N, Hammond R, Ditchfield H, Holt G, Martin J, Brooks D (2004) Psychiatric inpatient care for adults with intellectual disabilities: generic or specialist units?

Review question(s): 2.2

Organisations authors are involved with:
1. South London and Maudsley NHS Trust, York Clinic, Guy’s Hospital, London, UK
2. Institute of Psychiatry, York Clinic, Guy’s Hospital, London, UK
3. Estia Centre, Snowsfields, London, UK
4. Guy’s King’s Thomas’ School of Medicine, York Clinic, Guy’s Hospital, London, UK

Type of study: 2-group before-and-after study

Country: England, UK

Population: Adults with learning disabilities (LD) that require a psychiatric admission in 3 inner London boroughs

Quality score: -

Type of service: General adult mental health units, specialist learning disability mental health unit

Study aim

To evaluate the effectiveness of a specialist unit for people with a learning disability and mental health problems (MHP) and to compare admissions to the specialist unit and the general psychiatric unit.

How the unit operates

A 6-bedded specialist unit was set up in 1999 to provide comprehensive assessment of people with LD and mental health problems where this cannot be achieved in a community setting. Referrals were made through the local community learning disability teams. The study relates to the first 35 months of the service. During this time, n=39 people were admitted to the specialist unit and n=45 people with LD were admitted to general adult psychiatric wards.

Findings

Characteristics

The 2 groups were compared on gender, age, ethic group, legal status, autism and epilepsy. There were no statistically significant differences between the 2 groups on any of the characteristics. The mean age of the 2 groups was 34.55 and the percentage of males in the 2 groups 50.7%. The number of people admitted in both groups detained under the Mental Health Act 1983 was 41.6%.

Length of stay

There was a significant difference in the length of stay of people in the specialist unit remaining inpatients for longer (mean: 23.3 weeks; sd=14.1) compared to those admitted to generic psychiatric wards (mean: 11.1 weeks; sd=13.6).

You would expect this to be the case because of the role that the specialist unit provides in providing a comprehensive assessment, treatment and rehabilitation service so that people can be successfully reintegrated into the community rather than being a reactive response to crisis.

Residence on discharge

People in the specialist unit (3 out of 33) were less likely to be discharged to an out-of-area placement compare to those discharged from general adult mental health wards (10 out of 33).

Clinical outcomes

People treated in the specialist unit showed significant improvements on a number of outcome measures including psychiatric symptoms, overall level of functioning, severity of mental health problems and behavioural problems.

Capacity – inpatient services

In this study, 84 admissions were accounted for by 54 patients out of an active caseload of 320 adults with LD and MHP living in an area serving a total population of 680,000. That means just under 17% of the patients in contact with the community mental health and LD teams require inpatient care over the approximately 3-year period of the study.

Considerations

This study was not designed to be able to answer the question as to whether specialist units for people with LD and MHP are as effective as general adult mental health units. People were not randomly allocated to the groups and the outcomes of people in the generic group were not measured, so we don’t know if people in this group might have experience the same level of improvement as the specialist treatment group. Due to the small number of beds in the specialist unit and low turnover this meant that some admissions that might have been more appropriate for the specialist unit had to be directed to the generic wards.

The study also only assesses the outcomes of people at the time of discharge so we don’t know if the positive outcomes can be sustained over time. Also the outcome measures used in the study are not entirely independent from each other and are not all standard measures used with people with LD and MHP.

It is also worth noting that the study took place at only 1 site, with a modest number of participants so we cannot sure at how far they could scale up to be applicable to other areas of the UK.

Economics

No economic modelling was undertaken for this review question.

Evidence statements

For details of how the evidence is graded and on writing evidence statements, see Developing NICE guidelines: the manual.

AC6	**Lack of local specialist and crisis community services leads to out-of-area placements** There was evidence from 4 mixed quality studies Beadle-Brown et al. (2009,+), Pritchard and Roy (2006 −), Wong et al. (2015 −) and Hall et al. (2014+) that lack of specialist and crisis community services resulted in out-of-area placements. In a qualitative study by Beadle-Brown et al. (2009 +) (n=30), 8 out of 26 care managers who gave a reason for out-of-area placements said this was because of the lack of specialist services in the person’s local area. One mixed methods study (n=1239) (Pritchard and Roy 2006 −) found that out of area placements were due to local services being unresponsive to new crises, and a severe shortage of local forensic beds. Hall et al. (2014 +), in a cross-sectional survey (n=148), also found there is a severe insufficiency of low secure beds in the NHS, with many people placed a considerable distance away from home. The study found that different types of care should be integrated so that patients can progress to less restrictive settings (‘step-down’) as soon as is appropriate for their needs. Wong et al. (2015 −) in their retrospective review of hospital records found that a large proportion of people who had been referred to the hospital from outside their own area had a diagnosis of autistic spectrum disorder (ASD) (79.3%) compared to 58.6% of admissions who came from the hospital’s local area. Authors say this is because there is a lack of local, specialised services for this group of people. Over 40% of the out of area admissions aged 16 and younger, compared to 15.5% of admissions who came from the hospitals local area.
AC7	**Lack of accurate recording systems to plan local service needs**

	There was low quality evidence from 3 studies Pritchard and Roy (2006 −), NAO (2015−) NAO (2017 −) that there was a lack of accurate recording systems to plan local service needs. Pritchard and Roy (2006 −), in a mixed methods study (n=1239), identified a need for the development of a database to collect information about the needs of people and cost of care packages. If the information gaps were filled in the database it could help commissioners to develop appropriate local services. An NAO (2015 −) mixed methods audit of 2600 inpatients said lack of accurate recording systems prevent knowing local service needs and planning for them. The updated NAO audit (2017−), which also used mixed methods, also found that data in risk registers is particularly poor on people in the criminal justice system and on children about to enter the adult system so they are not identifying all people at risk or waiting to be admitted into mental health hospitals.
AC8	**Quality assurance of services** There was a mixed quality evidence from 1 cross-sectional survey, 2 mixed methods studies and 1 study of views and experiences: Pritchard and Roy (2006 −), Royal College of Psychiatrists (2013 −), NAO (2015 −), Beadle-Brown et al. (2009 +) that said there was a lack of the means to assure the quality of services. Pritchard and Roy (2006 −), in their mixed methods study (n=1239), found that some providers said that there was a need for an approved list of providers. This could help in choosing cost effective client-centred providers. The Royal College of Psychiatrists (2013 −) mixed methods report, which extrapolated from local data that between 22 000 and 26 000 people with a learning disability in England are likely to have some form of behaviour that challenges, recommended that providers should be accredited and meet stated outcomes. All inpatient units should be able to show evidence of going through an external accreditation process, such as those run by the Royal College of Psychiatrists or an equivalent. The NAO (2015 −) audit of 2600 inpatients, using mixed methods said that holding service providers to account was an essential part to ensuring a person has a sustained and successful community placement. In a qualitative study by Beadle-Brown et al. (2009 +) (n=30) families and providers said that it was more difficult to quality assure the out of area placements, it was difficult to find someone to take responsibility if things went wrong, they were thought to operate only at minimum standards. Without appropriate monitoring, standards could slip unnoticed, shortage of placements deterred families from complaining or raising issues.
AC9	**Shared commissioning for local services** There was evidence from 4 low quality studies (NAO 2015 -, NAO 2017;- Pritchard and Roy 2006 −; Royal College of Psychiatrists 2013 −) that said that shared commissioning for services could be more effective in meeting needs for people locally. Pritchard and Roy (2006 −), in a mixed methods study (n=1239), found that the justification for not meeting the needs of people with more complex needs was that it is viewed as not very cost-effective for an individual authority to meet the needs of a small numbers of people with specialist or complex needs. The study suggested that working together with neighbouring authorities with similar clients could lead to an affordable shared service. The study also found that 68% of the out of area

	placements were served by the private sector compared to 45% NHS providers for severe learning disabilities, and 80.5% of out of area placements for the complex needs group were served by the private sector, 2% voluntary and 7.5% NHS. The Royal College of Psychiatrists (2013 −) mixed methods' study which extrapolated from local data that between 22 000 and 26 000 people with a learning disability in England are likely to have some form of behaviour that challenges, said that there may have to be regional commissioning to ensure care pathway developed from hospital to home from the start, and complement community teams. The NAO (2017) report (n=2510 inpatients) said only a third of clinical commissioning groups had pooled their budgets with individual local authorities (taken from a survey of clinical commissioning groups). The NAO (2015 −) report of 2600 inpatients said that the lack of mechanisms for pooling budgets was a barrier to commissioning appropriate local services.
AC10	**People with learning disabilities and behaviour that challenges most at risk of out-of area-placements** Four studies of mixed quality said there were groups of people more at risk of out of area placements: Allen et al. (2007 −), Chaplin (2010 +), Pritchard and Roy (2006 −) and Wong et al. (2015 −). The categories of people at risk of being placed out-of-area were: • people with severe challenging behaviour (Allen, Chaplin, Pritchard and Roy) • people with mental health problems (Allen, Chaplin, Pritchard and Roy) • people with a diagnosis of autism (Allen, Wong, Pritchard and Roy) • younger people (Pritchard and Roy, Wong) • people of higher ability level, moderate learning disabilities (Pritchard and Roy) • people with offending behaviour (Chaplin) • people with physical disabilities (Pritchard and Roy) • males (Wong). Allen et al (2007 −), a cross-sectional study using multiple regression analysis (n= 1458 service users, data available for 901 people), which found that people with mental health problems, higher ability level, diagnosis of autism, or challenging behaviour to such a degree they are excluded from services were more likely to be placed out-of-area. The Wong et al (2015 −) retrospective review of hospital records also found that a large proportion of people who had been referred to the hospital from outside their own area had a diagnosis of ASD (79.3%) compared to 58.6% of admissions who came from the hospital's local area. The authors suggest this is because there is a lack of local, specialised services for this group of people. The Chaplin et al (2010 +) mixed methods study (n=55) found 3 distinct groups of people placed out-of-area for forensic services. These were: those with serious offending behaviour; those with severe challenging behaviour; and those with severe mental illness. The study suggested that,

	when developing capacity to provide services for this population, local pathways could be developed for each distinct group. Pritchard and Roy (2006 −) in a mixed methods study (n=1239), found that people with complex needs (mild or moderate LDs often associated with autism and mental health problems), people with severe challenging behaviour or people with severe learning disabilities with additional physical and behavioural problems aged 19–45 were more likely to be placed out-of-area. Over 40% of the out-of-area admissions aged 16 and younger, compared to 15.5% of admissions who came from the hospital's local area. There were 29 out-of-area admissions in 2011–13, of which there were more male admissions (n=25, 86.2%) than female admissions. The authors also found that 68% of the out of area placements were served by the private sector compared to 45% NHS providers for severe learning disabilities, and 80.5% of out of area placements for the complex needs group were served by the private sector, 12% voluntary and 7.5% NHS.
AC11	**Service needs of people with learning disabilities and behaviour that challenges in the community – integrating specialist and general** There was evidence from 4 mostly low quality studies that said a specialist service integrated with general services works well: Gangadharan et al. (2001 −), Slevin (2004 +), NAO (2015 −), Royal College of Psychiatrists (2013 −). In a cross-sectional study by Gangadharan et al. (2001 −), (n=49), specialist service provision was co-located alongside general (CAMHS) to service children and young people with more complex, multiple needs. The Slevin study (2004 +) was a survey (n=44) in which community learning disabilities nurses found that nearly a third (28%) of their caseload included people with behaviour that challenges. The nurses said additional training courses that specialised in behaviour that challenges helped them do their job better.
AC12	**Characteristics of behaviour that challenges that may be construed as offending or antisocial** There is a small amount of evidence from 2 moderate quality studies (McBrien et al. 2003 +; Wheeler et al. 2009 +) which talked about the characteristics of behaviour that challenges that may be construed as offending or antisocial. Wheeler et al. (2009 +) in a retrospective review of case notes (n=237) found that a high proportion of offences (37%) showed a pattern of repeat offending (more than 5 times, suggesting early intervention may be needed to prevent developing a pattern of repeat offending). Antisocial behaviour was thought to be present in between 3.8% and 17% of people with learning disabilities. The authors also found the ratio to be 5:1, that is the ratio of antisocial behaviour to offending behaviour, and that cases referred annually as a result of antisocial behaviour made up 3.8% of the established adult ID population. Both Wheeler et al. (2009 +) and McBrien et al (2003 +), in a cross-sectional survey (n=1326) found that the majority of the challenging behaviour is largely antisocial or 'risky' compared to actual offending behaviour.
AC13	**Sexual related behaviour** There is mixed evidence from 3 studies (Browning et al. 2016 −; McBrien et al. 2003 +; Seaward and Rees 2001 −) that talks about the prevalence of

	sexual related behaviour that may be described as behaviour that challenges. Browning et al. (2016 −) in their retrospective case note review (n=70) identified 52.9 % of people with learning disabilities referred to community forensic services for a sexual offence. In the Seaward and Rees (2001 −) cross-sectional survey (n=31), a small number of offences were prosecuted (2%), and these were more likely to be sexual offences. When asked about what was the nature of offences that community teams knew about their clients, there was a high proportion of offences that were sexual offences (37%) or were described as sexual behaviour-related risky behaviours (32%). McBrien et al. (2003 +) in a cross-sectional survey (n=1326) also found that 51% of the most frequent risky behaviour displayed in community services settings was sexual behaviour-related.
AC14	**Community-based forensic service needs for people with learning disabilities and behaviour that challenges that is considered antisocial or risky** There is a small amount of evidence from 1 good quality study (Wheeler et al 2009 +) about the service needs for people with learning disabilities and behaviour that challenges that is considered antisocial or risky. In a retrospective review of case notes (n=237), the authors found that people with learning disabilities and low level offending who are already in contact with LD services were are more likely to continue to be referred to community-based LD teams than to criminal justice agencies, but for people who enter via the CJS route and not in contact with LDs, they are less likely to be referred to the LD teams. This is particularly true for people with borderline learning disabilities.
AC15	**Contact with the criminal justice system (CJS)** There is a small amount of good quality evidence from 2 studies (McBrien et al. 2003 +; Wheeler et al. 2009+) that talked about the prevalence of contact with the CJS. Wheeler et al. (2009 +) in a retrospective review of case notes (n=237), found that of the 237 people referred for offending or antisocial behaviour,188 had no CJS contact and only 49 had CJS contact (21%). This study also found that 0.8% of the ID population known to services was referred annually because of behaviour that involved CJS contact. However, in people with mild to moderate ID (IQ range 50–70) there can be considerable ambiguity around which behaviours should be treated as 'offending' as opposed to 'challenging' or 'antisocial' and reported as such to CJS agencies. McBrien et al. (2003 +) in a cross-sectional survey (n=1326) found that people with ID who had offended, or were at risk of offending, had a prevalence of 26% of total population of people with intellectual disabilities; 63% of people in their study had no contact with the CJS but demonstrated 'risky behaviour'. This study also found that 128 (9.7% of people known to services) had a history of some contact with the CJS.
AC16	**Risky, not offending, behaviour** There is a small amount of good quality evidence from 2 studies (McBrien et al. 2003 +; Wheeler et al. 2009 +) that talked about the prevalence of behaviour described as "at risk of offending" behaviour.

	McBrien et al. (2003 +) in a cross-sectional survey (n=1326) included cases with similarly defined antisocial behaviour, and reported 17% prevalence in all settings (specialist and social care). The authors also found that 17% had challenging behaviour that was 'risky', but was not considered to constitute offending behaviour. Wheeler et al. (2009 +) in a retrospective review of case notes (n=237), found that of the 237 people referred to a community learning disability team for offending or antisocial behaviour, n=188 (79%) had no contact with the criminal justice system which is similarly defined 'at risk of contact with criminal justice
AC17	**What is the appropriate inpatient beds capacity?** Three studies tried to answer this question directly. Based on a survey and consultation, the Royal College of Psychiatrists (2013 −) mixed methods report which extrapolated from local data that between 22 000 and 26 000 people with a learning disability in England are likely to have some form of behaviour that challenges found the requirements of all categories of beds is about 6 to 7 per 100,000. Mansell et al. (2010−) in a cross-sectional survey (n=434) said that if services were spread more evenly across the regions (ranges from 1.75–24.19 per 100,000), this would average out to 6.06 per 100,000. This was for assessment and treatment units, low secure and moderate secure units. The 2015 Learning Disability Census (HSCIC 2015 +) found that 2340 patients (78%) were recorded as having a treatment reason that indicated they needed inpatient care and 2050 patients (68%) had a care plan status that suggested that the patient needed to remain in inpatient care.
AC18	**Identified shortages of inpatient capacity** Three studies of mixed quality (Hall et al. 2014 +; HSCIC 2015 +; Mansell et al. 2010 −) identified shortages of inpatient capacity. Mansell et al. (2010 −) in a cross-sectional survey (n=434) found that the assessment and treatment centres that were provided by independent healthcare (IH) providers were larger compared to NHS providers and were more likely to be fully occupied compared to NHS units. The Hall et al. (2014 +) cross-sectional survey (n=148) reported that there is a severe insufficiency of low secure beds in the NHS, with many people placed a considerable distance away from home. The 2015 Learning Disability Census (HSCIC 2015 +) where (n=3000) found that the proportion of patients receiving care in low secure wards reduced to 27% (810 patients) compared to 37% (1195 patients) and 31% (1015 patients) on census day 2013 and 2014 respectively. In 2015, 1575 patients (53%) were receiving care in general wards; the highest proportion in all 3 census collections. The 2015 census also said that 42% of patients were admitted to hospitals over 50km from their home area. This is up from 36.7% in 2013 which indicated a lot of people are still being placed out-of-area. According to the latest data from NHS Digital (2017), at the end of November 2016 there were 528 out of area placements active, of which 95% were due to unavailability of a local bed (an inappropriate out of area placement). This only includes out of area placements that started on or after 17 October 2016.
AC19	**Delayed discharges**

	Three low quality studies (HSCIC 2015 +; Mansell et al. 2010 −; Oxley et al. 2013 −) identified problems with delayed discharges. Mansell et al. (2010 −) in a cross-sectional survey (n=434), reported that NHS units had more patients who had finished active treatment but did not have any plans to leave the service in the next month compared to IH units. Assessment and treatment units had a higher proportion of such patients (at 25%) than low (10%) or medium (3%) secure units. None of the IH providers said they had people who had finished treatment without plans to leave in the next month. However, Oxley et al. (2013 −), in a retrospective review of hospital admission records (n=101) between 1999-2011 found that 'social admissions' were the third most common reason for admission. Social admissions do not have anything to do with clinical need, but have to do with reasons such as having discharges delayed because of finding funding for a suitable placement. This was the case in the first study period and also the second. The 2015 Learning Disability Census (HSCIC 2015 +) where (n=3000) said that 145 patients (5%) were recorded as having a delayed discharge due to placement unavailability – 41% of delays were due to 'waiting for residential home availability'; 20% were due to waiting for further non-acute NHS care; 14% were due to waiting for an assessment to be completed; and 8% of delays were due to 'waiting for public funding'. For young people under 18 (165, 6%), 4% were recorded as having a delayed discharge due to placement unavailability. The 2015 census (HSCIC 2015 +) also found that in 32% of cases delayed discharge was attributed to healthcare delays by the NHS. In 34% of cases, the delays were primarily attributed to social care, and in 23% of cases both agencies were considered to share the responsibility.
AC20	**Planning for discharge** Three mixed quality studies (Buxton et al 2004 −; Devapriam et al. 2014 +; Mansell et al 2010 and Learning Disability Census (HSCIC 2015 +) talked about planning for discharge. Buxton et al. (2004 −), a process evaluation (n=not specified) and Devapriam et al. (2014 +), an evaluation of a single group (n=24), found that establishing a care pathway in an inpatient setting can prevent delayed discharge by increasing patient flow, and increasing capacity for inpatient settings, preventing the need for OAPs. Mansell et al. (2010 −), in a cross-sectional survey (n=434), found that a large proportion of people in assessment and treatment units and low secure units did not have a care plan (55%, 44%). This compares to only 14% in medium secure units who did not have a care plan. The 2015 Learning Disability Census (HSCIC 2015 +) where (n=3000) said that all inpatients had a care plan: 805 patients (27%) were reported to have a care plan record of 'working towards discharge' while 145 patients (5%) were recorded as having a delayed transfer due to placement unavailability. It also found that the average 'approximate rate of discharge' for England was 39% between 2014 and 2015.
AC21	**Length of stay: specialist disability unit** Three mixed quality studies (HSCIC 2015 +; Oxley et al. 2013 −; Wong et al. 2015 −) reported on the average length of stay in a specialist disability unit.

	Oxley et al. (2013 −), in a retrospective review of hospital records (n=101) found that the average (mean) length of stay/days in 1999–2001 was 198.6 and in 2003–11 it was 244.6. Length of stay tends to be longer in specialist units. Wong et al. (2015 −) in their retrospective review of hospital records found that 9 out of 58 (67.2%) admissions had stayed over 6 months in 2011–13, accounting for the majority of total admissions. The number within the shortest admissions (1 to 3 months) category had also increased from 7.8 to 15.5%. The 2015 Learning Disability Census (HSCIC 2015 +) where (n=3000) found that 1190 patients (40%) had a length of stay up to 1 year; 1300 patients (43%) had a length of stay between 1 and 5 years; 510 patients (17%) had a length of stay of 5 years of more; 1620 patients had received continuous inpatient care between the 2014 and 2015 census collections. Of the 3000 people receiving inpatient care on census day 2015, 1450 (48%) were receiving care at the time of all 3 censuses.
AC22	**Length of stay: inpatient forensic services** Two mixed quality studies (Hall et al. 2014 +; Vaughan 2003 −) reported on the length of stay in inpatient forensic services. Vaughan (2003 −), in a cross-sectional survey (n=35), reported that inpatient category 1: high, medium and low secure forensic beds mean length of stay was 3 years and 7 months (range =2 months–12 years). However, there were 3 exceptionally long placements and the median length of 2 years and 4 months is more representative. Hall et al. (2014 +), in a cross-sectional survey (n=148), reported on forensic inpatient length of stay – maximum and average (years). There was little difference between the low and medium secure groups in terms of length of stay, except for the longest stay in the low secure with forensic services unit. The 2015 Learning Disability Census (HSCIC 2015 +) where (n=3000) found that the proportion of patients with a length of stay of over 1 year is higher in secure wards. Breakdown of a length of stay of more than 1 year: • 620 patients (77%) on a low secure ward • 375 patients (72%) on a medium secure ward • 60 patients (91%) on a high secure ward. Of those in a high secure ward, 59% (40 patients) had been in these settings 5 years or more.
AC23	**Need for specialist as well as generic services** There is some low quality evidence from 2 studies (Purandare 2015 −; Xenitidis et al. 2004 −) that suggests there is a need for specialist inpatient services for people with a learning disability and more complex needs including behavioural problems or mental health problems. Xenitidis et al. (2004 −), a 2-group before-and-after study (n= 84) looked at the differences in what happened to people with a learning disability and mental health problems admitted to different types of inpatient services. They found that there weren't any significant differences in the characteristics of people with learning disabilities and mental health problems treated by the different inpatient services. People admitted to a specialist unit stayed longer than people admitted to a general mental health ward but they were less likely to be discharged to an OAP. A

	significant proportion of people (10 out of 45) were admitted to both types of unit. In Purandare's (2015 −), retrospective review of hospital records (n=79 referrals) over half the admissions during the study period (54%) had been first admitted to a mainstream mental health ward but then needed to be transferred to the specialist unit as the generic service reasons for transfer included: • the need for specialist behavioural assessment and treatment. • there was a lack of appropriate training in generic mental health units • there was a need for environmental adaptations to suit the needs of patients with autism.
EcAC1	**Differences in accommodation types for in-area vs. out-of-area placements** Allen et al. (2007 -), a cross-sectional study using multiple regression analysis (n= 1458 service users, in which data were available for 901 people), focused on adults with intellectual disabilities and found that in-area residents were living in family homes (27%) and staffed homes (55%) whereas out-of-area residents were living in mainly larger-scale institutional settings (52%) and staffed housing (34%). We do not know whether certain characteristics are associated with different types of accommodation.
EcAC2	**Access and frequency to services and care planning** Allen et al (2007), a cross-sectional study using multiple regression analysis (n= 1458 service users, in which data were available for 901 people) compared adults with intellectual disabilities living in-area placements compared to out-of-area placements and found that both in-area and out-of-area had: • low levels of access and use of advocates • similar levels of access and frequency of support from social work and speech and language therapists. Out-of-area placements had: • slightly higher access and use of psychologists, psychiatrists and care managers (50.5%, 56.7%, 64.9%) compared to in-area placements (42.7%, 36.7%, 47.7%) • higher percentages with a behaviour plan (63%) compared to in-area placements (30%). It is not clear whether access to professionals was provided directly by receiving organisations or from the public sector. The implication is that out-of-area placements place additional pressure on local services and might undermine access for local service users Knapp et al. (2005 +/+), a cross-sectional study (n= 930), analysed the individual and service factors influencing costs and patterns of service use and found that access to services was poor across mainstream health services, including: • day activity services • primary care services • community health services.
EcAC3	**Comparing costs of in-area vs. out-of-area placements**

	Allen et al. (2007 −), a cross-sectional study using multiple regression analysis (n= 1458 service users, in which data were available for 901 people), focused on adults with intellectual disability and found that the average cost of an out-of-area placement was £96,000/year (2002/03 prices). The authors did not provide the average costs for in-area placements. Pritchard and Roy (2006 −), in a mixed methods study (n=1239), found that for adolescents and adults with learning disabilities and complex mental health needs, out-of-area placements cost more – £97,509/year – compared to in-area placements – £74,767/year (2002/03 prices). This is likely a result of the finding that a greater percentage of individuals in out-of-area placements (33.5%) had the highest-cost placements (£90,000+/year) than for in-area placements, (19.5%). Adolescents and adults with a severe learning disability and high levels of support needs/physical and behaviour problems had slightly higher but similar costs. Out-of-area placements had an average cost of £46,524/year compared to in-area placements, £42,776/year (2002/03 prices). The distribution of costs was very similar for both out-of-area and in-area placements. For both populations, it is not clear why costs are higher as no further analyses were undertaken. Furthermore, a limitation is that it is not clear whether differences in costs, for both population groups, were statistically significant, as this was not reported. Deveau et al. (2016 +), in a cross-sectional survey (n=105) focused on a subgroup of adults with intellectual disabilities with the highest-cost care packages and found that the cost of in-area and out-of-area placements were not different, the same finding as that in the earlier 2009/10 survey. The mean cost of an out-of-area placement was £202,000, compared to an in-area placement of £198,000 (2011 prices). The mean placement cost for all placements (in-area and out-of-area) was £200,000 with a range between £81,00 and £430,000 (2011 prices). Overlaps in the predictors of both higher cost placements and being placed out-of-area include offending behaviour. The average costs of individuals with offending behaviour were £226,000/year compared to £192,00/year for individuals without offending behaviour (2011 prices). Hassiotis et al 2008 (+), in a survey (n=205) focused on a subgroup of adults with intellectual disabilities and challenging behaviour who had the highest-cost care packages and found that out-of-area placements had higher care package costs compared to those placed in-area. Total mean (median) care package costs of in-area placements were £97,893 (£88,959) vs. out-of-area placements, £105,952 (£90,345). It is not clear whether differences in costs are statistically significant. Predictors of being placed out-of-area included: having mental health problems or autism were not statistically associated with being placed out-of-area but a majority of individuals with those conditions were placed out-of-area, however, these same characteristics were statistically associated with higher cost placements and support packages; younger age and living in certain boroughs. Managers' assessments that individuals' have greater needs, which is consistent with the finding that these individuals have higher levels of challenging behaviour)

EcAC4	**Adolescents aged 16-18 transitioning to adult services, costs and service use** Barron et al (2013 +), in an observational study, focused on a small sample (n=27) of adolescents aged 16-18 years old with various levels of intellectual disability and challenging behaviour who are at the transition stage into adult services. Notable characteristics • 52% males • Intellectual disabilities: 41% mild, 41% moderate, 18% severe • Challenging behaviour: average score was 16.8 (sd=11.1, range 0–36 using the Challenging Behaviour Checklist), 55% had a score of 17+ • Most lived in parental home (70%), followed by out-of-area specialist residential (19%), foster care (7%), and supported accommodation (4%, n=1) Individual characteristics and relationship to costs More severe intellectual disability was associated with higher total costs. There was no relationship between costs and level of challenging behaviour or number of physical or mental health diagnoses. Cost components Informal care comprised 66% of total costs, with informal carers providing an average of 89 hours/week. Education costs comprised 22% of total costs, followed by community-based services (8.7%), daytime activities (3.4%), and hospital services (0.4%). Employment services were not accessed by any of the sample members (0%). Notable service use 89% of the sample were in full-time education. Community-based services most frequently used in the past 6 months Social worker (85%), dentist (67%) ,speech and language therapist (63%), art/drama/music therapist (44%), GP (41%), other community nurse (41%). Least frequently used community services in past 6 months Chiropodist (4%), community psychiatric nurse (4%), intellectual disability nurse (4%), occupational therapist (15%), alternative therapist (19%), advocate counsellor (22%), optician (22%), clinical psychologist (26%), home help/home care worker (26%), psychiatrist (30%), other community services (37%).
ECU2	**Costs/ service use and associations with child/parent characteristics (aged 2–9 years old)** There is limited evidence from 1 small UK cross-sectional study based on a convenience sample (n=49) over a 6-month period that has good external validity (++) and moderate internal validity (+) (Adams et al. 2016 +) (n=49). The sample comprises mothers and their children aged between 2–9 years old who have intellectual disability or global developmental delay and challenging behaviour. The study finds that children with challenging behaviour that display aggression or destruction of the environment use 1.9 and 2.5 times more community-based healthcare services than children with challenging behaviour not displaying those behaviour but no significant differences in use of hospital services. For children with or without self-injurious behaviour, there were no differences in either community or hospital-based

	healthcare services. Furthermore, children with 2 or 3 forms of challenging behaviour use approximately 2 times more community-based healthcare services than children with 0 or 1 forms of challenging behaviour, but they were not different in their use of hospital healthcare services. The authors conclude that this suggests a need for effective and accessible early intervention services for children with more than 1 form of challenging behaviour and challenging behaviour in the form of aggression or destruction of the environment.
ECU3	**Costs and service use associated with community learning disability teams and adult characteristics** There is limited evidence from 1 small, moderate quality UK longitudinal study over a 12-month period that used a convenience sample (n=61) (Unwin et al 2016, +). The sample comprises adults with intellectual disability and aggressive behaviour, recruited from 10 psychiatrist-led community learning disability teams. This study only included the costs of medication and the costs of contacting community learning disability services (i.e. the costs of contacting different professionals within the service). Higher costs were associated with male gender (£909, sd=786) (n=37) compared to females (£594, sd=679) (n=23) (p=0.02); epilepsy (£1143, sd=779) (n=16) compared to those without epilepsy (£659, sd=716) (n=44) (p=0.03); and those who were able to communicate verbally (£896, sd=836) (n=43) compared to those were non-verbal (£514, sd=418) (n=17) (p=0.01) (p.5, 6). These 3 factors were able to predict 23% of the variance in 12-month costs (p=0.002) (p5). No other characteristics had a statistically significant relationship with service use/costs. However, there was a trend of higher average costs for the following characteristics: younger age, those living in family homes (vs. those in staffed community houses), those with autism and those reaching the threshold for psychiatric diagnosis. Level of intellectual disability and severity of aggression had even less strong associations with service use, but there were still some levels of association between greater aggression and higher costs and mild/moderate disabilities and higher cost (pp6, 8).

For Guideline Committee discussion of the evidence see the Evidence to Recommendations tables in Section 3.7.

Included studies for these review questions

Adams D, Handley L, Simkiss D et al. (2016) Service use and access in young children with an intellectual disability or global developmental delay: Associations with challenging behaviour. Journal of Intellectual & Developmental Disability, 1–10

Allen DG, Lowe K, Moore K et al. (2007) Predictors, costs and characteristics of out of area placement for people with intellectual disability and challenging behaviour. Journal of Intellectual Disability Research 51, 409–16

Barron D, Molosankwe I, Romeo R et al. (2013) Urban adolescents with intellectual disability and challenging behaviour: Costs and characteristics during transition to adult services. Health and Social Care in the Community 21(3), 283–92

Beadle-Brown J, Mansell J, Whelton B et al. (2009) People with learning disabilities in 'out-of-area' residential placements: views of families, managers and specialists. The British Journal of Developmental Disabilities 55, 15–31

Browning M, Gray R, Tomlins R (2016) A community forensic team for people with intellectual disabilities. Journal of Forensic Practice 18, 274–82

Buxton L, Pidduck D, Marston G et al. (2004) Development of a multidisciplinary care pathway for a specialist learning disability inpatient treatment and assessment unit. Journal of Integrated Care Pathways 8, 119–26

Chaplin E, Kelesidi K, Emery H et al. (2010) People with learning disabilities placed out of area: The South London experience. Journal of Learning Disabilities and Offending Behaviour 1, 5–14

Devapriam J, Alexander R, Gumber R et al. (2014) Impact of care pathway-based approach on outcomes in a specialist intellectual disability inpatient unit. Journal of Intellectual Disabilities 18(3), 211–20

Deveau R, McGill P, Poynter J (2016) Characteristics of the most expensive residential placements for adults with learning disabilities in South East England: A follow-up survey. Tizard Learning Disability Review 20 (2), 97–102

Gangadharan S, Bretherton K, Johnson B (2001) Pattern of referral to a child learning disability service. British Journal of Developmental Disabilities 47 part 2, 99–104

Hall I, Yacoub E, Boast N et al. (2014) Secure inpatient services: A needs assessment. Journal of Intellectual Disabilities and Offending Behaviour 5, 38–53

Hassiotis A, Parkes C, Jones L et al. (2008) Individual characteristics and service expenditure on challenging behaviour for adults with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 21, 438–45

Health and Social Care Information Centre (2015) Learning Disability Census report: England 30 September 2015 experimental statistics. London: Health and Social Care Information Centre

Knapp M, Comas-Herrera A, Astin J et al. (2005) Intellectual disability, challenging behaviour and cost in care accommodation: What are the links? Health & Social Care in the Community 13, 297–306

Local Government Association (2016) Learning disability services efficiency project. London: LGA

Mansell J, Ritchie F, Dyer R (2010) Health service inpatient units for people with intellectual disabilities and challenging behaviour or mental health problems. Journal of Applied Research in Intellectual Disabilities 23, 552–59

McBrien J, Gregory J, Hodgetts A (2003) Offending and risky behaviour in community services for people with intellectual disabilities in one local authority. Journal of Forensic Psychiatry and Psychology 14, 280–9

National Audit Office (2015) Care services for people with learning disabilities and challenging behaviour. London: NAO

National Audit Office (2017) Local support for people with a learning disability. London: NAO

Oxley C, Sathanandan S, Gazizova D et al. (2013) A comparative review of admissions to an intellectual disability inpatient service over a 10 year period. British Journal of Medical Practitioners 6(2): a611

Pritchard A, Roy A (2006) Reversing the export of people with learning disabilities and complex health needs. British Journal of Learning Disabilities 34, 88–93

Purandare K, Wijeratne A (2015) Reflections on the use of a specialist acute assessment and treatment unit for adults with intellectual disability. Advances in Mental Health and Intellectual Disabilities 9, 132–38

Royal College of Psychiatrists (2013) People with learning disability and mental health, behavioural or forensic problems: The role of inpatient services. London: PCPsych

Seaward S, Rees C (2001) Responding to people with a learning disability who offend. Nursing Standard 15, 36–9

Slevin E (2004) Learning disabilities: a survey of community nurses for people with prevalence of challenging behaviour and contact demands. Journal of Clinical Nursing 13, 571–9

Unwin G, Deb S, Deb T (2016) An exploration of costs of community-based specialist health service provision for the management of aggressive behaviour in adults with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, advance online publication: doi:10.1111/jar.12241

Vaughan PJ (2003) Secure care and treatment needs of individuals with learning disability and severe challenging behaviour. British Journal of Learning Disabilities 31, 113–17

Wheeler JR, Holland AJ, Bambrick M et al. (2009) Community services and people with intellectual disabilities who engage in anti-social or offending behaviour: referral rates, characteristics, and pathways. Journal of Forensic Psychiatry & Psychology 20(5), 717–40

Wong YL, Bhutia R, Tayar K et al. (2015) A five decade retrospective review of admission trends in a NHS intellectual disability hospital. Advances in Mental Health and Intellectual Disabilities 9(3), 108–15

Xenitidis K, Gratsa A, Bouras N et al. (2004) Psychiatric inpatient care for adults with intellectual disabilities: generic or specialist units? Journal of Intellectual Disabilities Research 48(1), 11–18

3.3 Models of service delivery

Introduction to the review questions

The purpose of this review, which comprises 3 questions, was to assess the effectives of different models of service delivery. By 'service models' we mean broad approaches to arranging services or support and how they work together. We also reviewed what people said about their views and experiences of different models of service delivery.

Current policy in England and Wales already sets out what a good service delivery model should look like (NHS England) and while there is broad agreement about this, the Guideline Committee noted that it isn't always happening in practice. For this reason, the review group also included studies that could help us understand how a good model should work in practice.

Effectiveness studies – we did not find very much evidence of the kind that compared different models of service delivery in such a way that could tell us whether 1 model was any more effective than another and for this reason most of the studies we included were assessed to be of low quality. We sought evidence from an expert witness on best practice for supporting people with learning disabilities (including children) – the Devon case study described the views and experiences of a service that worked well and did not work well for a young woman with learning disabilities and behaviour that challenges, her mother, the learning disability service commissioner and service provider. The evidence is summarised in the expert testimony section under 3.3.

Qualitative studies – these studies ask people about their views and experiences. This can be useful to see what helps or gets in the way of delivering good care for different types of services.

Review questions

3.1. What models of service delivery are effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers?

3.2. What models of service delivery are cost-effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers?

3.3. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different models of services delivery?

Summary of the review protocol

This review question sought to assess the relative impacts and cost-effectiveness of different models of service delivery, their content, configuration and acceptability to meet health and social care needs and to assess the barriers and facilitators to implementing models of service delivery.

Full protocols can be found in Appendix A.

Population

People with a learning disability and behaviour that challenges, parents, families or carers of people with a learning disability and behaviour that challenges. Professionals who work with people with a learning disability and behaviour that challenges.

Intervention

Community-based services, inpatient services, models of service delivery.

Setting

All settings where care is delivered.

Person-focused outcomes

Child development outcomes; continuity of care; families and carers stress and resilience; frequency, severity and duration of behaviour that challenges; health and social care-related quality of life; inclusion in community life; service user involvement in planning, delivery and monitoring of services; service user, family and carer satisfaction.

Service-focused outcomes

Availability, access and uptake of local services; equity of access; meeting complex, physical and mental health needs; geographical variation in service provision (locally, regionally and nationally); level and type of support from care workers and carers; positive behaviour support; timely discharge; out-of-area placements; use of inpatient services.

Phenomena of interest (for views and experiences studies)

Barriers and facilitators to access to services; experiences of stress and resilience; preferences and values; involvement in the planning, delivery and monitoring of services; inclusion in community life; independence.

Study designs

Systematic reviews of effectiveness studies; systematic review of views and experiences; randomised controlled trials (RCTs); non-randomised controlled trials; studies of cost-effectiveness; qualitative studies of people's views and experiences.

See Appendix A for full protocols.

How the literature was searched

A search strategy for all of the review questions combined was developed and the questions were translated into a framework of 5 concepts of: a) population (people with a learning disability and behaviour that challenges), and b) service provision (including models of services and service capacity) or c) risk management or safeguarding or d) integrated services or e) access to services. These reflected the question areas: types of service provision, service capacity, service delivery and integration of services. The search strategy was run between December 2015 and January 2016 and update searches were conducted between February and March 2017. See Appendix A for full details of the search.

How studies were selected

Results from the searches were stored in EPPI-reviewer 4 a software program designed for information management of systematic reviews. The titles and abstracts of these results were screened against inclusion criteria that was developed from the scope. Two reviewers looked at the same studies' titles and abstracts independently of each other and compared their results to make sure that the inclusion criteria was understood and applied in the same way by both reviewers.

Studies that were found to meet the initial inclusion criteria were assigned to the relevant review question and the full text was retrieved for a second screening against the criteria in the protocol.

The review team found 192 studies relevant to this review question based on the title and abstract. After screening against the full text, 32 met the inclusion criteria and were included for these review questions. Eighteen studies looked at the effectiveness of models of services delivery and 10 were studies about people's views and experiences of services. We found 3 good quality systematic reviews that were about people's views and experiences of services and 1 study was a mixed methods study that looked at both effectiveness and people's views. Nine studies were included to answer the cost-effectiveness question. See Appendix B for full critical appraisal and findings tables.

Narrative summary of the evidence

Below are the narrative summaries of included studies, including economic and cost-effectiveness studies where identified.

Ahmad F, Bissaker S, DeLuc K, Pitts J, Brady S, Dunn L, Roy A (2002) Partnership for developing quality care pathway initiative for people with learning disabilities. Part I : development

Review question(s): 3.1, 3.2

Organisations authors involved with:

1. Partnership for Developing Quality, Birmingham

2. North Warwickshire NHS Trust, Birmingham

3. Moseley Hall Hospital, Birmingham

4. Hereford Integrated Learning Disability Service, Hereford.

5. Birmingham Community Health NHS Trust, Birmingham

Type of study: Process evaluation – the authors tell us that care pathways have been shown to be effective in other areas, like medicine, they say that care pathways have not, however, been put in place widely in treatment and assessment centres for people with learning disabilities and think this could be because of the complexity of people's needs

Country: England, UK

Population: People with learning disabilities and epilepsy, hearing loss and behaviour that challenges

Quality score: -

Type of service: A care pathway

Study aim

In this paper the authors detail the development phase of the project to put in place care pathways. They look at the things that are common to putting in place 3 separate care pathways: 1 for epilepsy, 1 for challenging behaviour and 1 for hearing impairment.

Findings

The authors identify a number of things they think are important for people to think about when they plan how to put a care pathway in place.

Help from a cross-regional clinical governance body – this means a group of people who work across different locations to make sure clinical care is being delivered properly.

How the local pathway work relates to what is happening in national policy.

Hiring different professionals with different skills.

Appointing 'facilitators' for each care pathway. The job of a facilitator in a process is to help things run smoothly. They can also, for example, help to keep people focused on what needs to be done.

Training on care pathways for different working groups.

Using a ‘generic’ process map template. A process map document usually sets out the steps people take to get something done, or to move through a system. A ‘generic’ document means it is not specific to 1 service only – it could be changed by different professionals so it relates to their service.

Having a ‘mission statement’ – a mission statement is a few words or a sentence that sets out, simply, what everyone is trying to do.

Doing a literature review and search for previous relevant care – the idea here is that local care pathways should build on what we already know about what works well for a particular need or service.

Making sure that the first stage of the care pathway includes a coordinator.

Having ways to keep track of when things are being done very differently in 1 place to another.

‘Scoping’ of documentation – this means having a first look at the sort of documents people have and what is in them. The idea is that knowing more early on can help you plan things better.

Testing out the care pathway with different sites. This could mean places that are very different, or that have very different services, or where people have different needs.

Evaluating what the current arrangement of services is like.

Considerations

The study was only partially relevant to us because the pathway for people with behaviour that challenges was 1 of the 3 care pathways that the group looked at and the pathway template they developed could be applied to all 3 user groups.

The design of the study was limited for a number of reasons.

The study said that there would be an evaluation of the pilot to be published in the same journal. This did not happen because the journal does not exist anymore. We could not find any later work done on this pilot. We do not think it is possible to draw conclusions about how well this approach works for developing a care pathway from this study alone.

Alborz A (2003) Transitions: Placing a son or daughter with intellectual disability and challenging behaviour in alternative residential provision

Review question(s): 3.3

Organisations author involved with:

1. National Primary Care Research and Development Centre, University of Manchester

Type of study: Qualitative

Country: England, UK

Population: Interviews were with family carers of children and adults with intellectual disabilities and showing behaviour that challenges

Quality score: ++

Type of service: Moving from the family home to a residential setting

Study aim

In this study the author looks at why people with intellectual disabilities and challenging behaviour move out of home to a different place to live. The author wanted to know if there are different reasons for moving and to test whether the reasons for people moving fitted into the categories below:

'normative' – the decision to leave home is made at about the same time and for the same reasons as most people,

'stress process' – the decision to move is based on a stressful situation,

'postponed' – where a person might stay in the family home longer than might be expected for their age.

Findings

The study found 7 different factors that explained a move out of home to alternative accommodation. We have grouped them into similar themes that we found in other studies that asked people about their views and experiences.

Access to support

Some parents said that not being able to access services and support meant they couldn’t cope in the long run, or needed to seek help elsewhere.

Choice and control

There were 2 factors that related to choice and control. Either the parents decided that their son or daughter should lead a separate, less dependent life or the son or daughter felt bored or frustrated and ready to move.

Family life

Parents sometimes found severe challenging behaviour at home difficult to cope with. Sometimes other difficulties in the family – like divorce, or mental/physical illness of spouse or siblings – affected their ability to cope.

Most families (14 out of the 18 involved) decided to look for alternative accommodation because life with the person at home was very difficult.

Health and wellbeing

Some parents said it was their health and wellbeing that affected the decision. Some had health issues themselves. Sometimes they said they felt ‘worn out’ or at the ‘end of their tether’ (p79).

Stress and strain

One factor related specifically to stress and strain. Parents sometimes said that it was challenging behaviour that made them look for a change. They said this was because it lasts a long time without getting better and it was difficult and upsetting to see how this affected their son or daughter.

Transition

The 7 factors that were identified from the interviews were:

1. Independence (n=6)

2. Bored – ready to move (n=3)

3. Severe challenging behaviour (n=11)

4. Lack of services, including respite (n=7)

5. Family problems (n=5)

6. Challenging behaviour – wearing (n=9)

7. Parent exhaustion or ill health (n=8)

Overall, the author found that most moves were down to stress, and not the ‘normative|’ reasons for moving home.

Things that helped

Supporting the family

The author suggests that if better family support were put in place, this could help people move to a different place to live before a crisis means they have to. This includes improving access to or less exclusion from day or respite services.

Considerations

The study involves a small number of people living in the North West Regional Health Authority area in the UK. We do not know if the experiences of these people are the same as those of others who move from home to alternative accommodation.

Having said that, the findings are consistent with what we have learned from other studies.

Study limitations

The parents were asked to think about events that, for some, were a long time ago (up to 6 years ago). The study itself is more than 10 years old and the participants were identified from a survey conducted in 1993. It is not clear when the interviews for this study happened.

Ayres M, Roy A. (2009) Supporting people with complex mental health needs to get a life! The role of the supported living outreach team

Review question(s): 3.1, 5.1, 5.2
Organisations authors involved with:

1. Supported Living Outreach Team, South Birmingham PCT

2. Consultant psychiatrist, South Birmingham PCT

Type of study: Process evaluation looking at how an intervention might work, but not addressing whether the new way of doing things is effective or not comparing it to how things are usually done

Country: England, UK

Population: Adults with learning disabilities and behaviour that challenges

Quality score: -

Type of service: Supported living services, to enable people with learning disabilities and behaviour that challenges to live safely in their local area

Study aim

This study looks at how the supported living outreach team (SLOT) works in Birmingham. The authors describe why the team was set up and how it works. The authors also look at some of the outcomes of the service. They talk about the hurdles and barriers the team has had to overcome in supporting people with learning disability and complex needs to live safely in their local communities.

How the SLOT team operates

The team sets up person-centred care packages, implements them and provides ongoing monitoring and support to individuals and service providers. The team will also take over direct provision of a service, if a service fails, until a new service is put in place.

The team provides clinical advice and support to the person, the home care provider and housing provider.

The team providing the service consists of: a clinical nurse manager, 5 clinical team leaders, 2 nurses and 3 support workers. All clinicians are registered learning disability (RNLD) nurses, some having further expertise in behaviour therapy, mental health, autism and person-centred facilitation. The team gets regular input from other services (psychological, speech and language, occupational therapy and psychiatry). The team has multi-professional input at both clinical & strategic level. The cost of the team is £490,000 per year (2008/2009 prices)

Once a long-term supported living scheme is in place and it appears to be going well and any associated risks are managed, the team will work towards discharging the individual from SLOT.

The authors note that this approach has been in place for 7 years.

Findings

The authors say the SLOT have achieved the following service outcomes:

- significant decrease in levels of risk and reductions in challenging/forensic behaviour,
- decrease in the use of as required (PRN) medication,
- increase in independent livings skills for many service users,
- prevention of breakdown of placements for clients in crisis, resulting in fewer out-of-area placements and admissions to hospital,
- earlier local discharge of existing inpatients,
- decrease in hours of support,

The authors also say that some issues have emerged that the service has learned from and point to some things that can help the service work better, such as the following.

Developing flexible teams around highly complex individuals. The staff team was doubled for some individuals with complex needs. The authors say that this worked because more staff got to know the individual and it allowed replacements of staff at short notice with minimal disruption to the service. Debriefings, following an incident with both staff and service users, also helped the team approach to work better.

Developing good relationships and ways of working with neighbours, local councillors and antisocial behaviour teams to address any concerns in local neighbourhoods. The authors say some service users have displayed behaviours not previously exhibited or reported in previous medical/nursing reports and these can affect local communities, so the development of good relationships with the community is important for this reason also.

'Admission proof' services. The authors say that 1 of the key reasons for the success of the team is that they have developed effective partnership arrangements with independent sector providers and the local community team, so, where possible, they can manage crises in an individual’s home, with familiar, dedicated staff and prevent readmission to hospital.

Another thing that the team did to help secure local housing for people was to set up a property damages fund. This was to persuade landlords and housing associations to offer tenancy agreements to individuals with a history of severe property damage. It was set up by the service commissioner to cover such costs and the SLOT had responsibility for overseeing the fund. The fund offered support and reassurance to landlords and it helps enable the service users to secure local housing at affordable rents.

Costs

This study is not an economic evaluation. This study reports on the costs of the intervention but methods of costing are not reported in detail, which is a limitation of the analysis. This study reports on changes in adults' care package costs and reductions in levels of staffing support.

The study authors report reductions in the care package costs of four adults over a 2-year period, which the authors attribute to adults having lower levels of risk and therefore needing lower levels of support. Reported savings for each of the four adults range between 5%, 34%, 37%, and 53% (p.37). These savings are partly based on actual cash savings but also on the assumption that care package costs would have been higher, in line with inflation, had there been no changes in individual's level of risk and corresponding support needs.

The authors do not provide comprehensive detail as to where cost savings were achieved but they do report that part of the reduction in care package costs were linked to reductions in direct staffing support (-43%) and home visits (-59%), but that indirect support (telephone support) had increased (70%) (p.37). The authors only report changes in staffing costs for a 1-year period.

Limitations of the costing analysis

Based on this study design, it is not possible to come to a conclusion as to whether this type of service is or is not cost-effective. In addition, the estimates of cost savings are based on 4 individuals, and caution is advised before drawing conclusions based on a small sample. Furthermore, unit costs used in the study reflect local prices, which mean that the findings on costs are not necessarily generalisable to other parts of the UK.

Considerations

The study was done by people involved with running the service. While they might be the ones that know the most about the service, they might be more likely to present a positive picture of the service. The authors have not acknowledged this and haven't tried to include any alternative perspectives on the service from either service users or other service providers that work closely with the service to provide a more balanced view.

Another thing to consider is that while some outcomes have been reported on in the study, they have not been reported in enough detail for us to be confident about the extent of the positive effect.

On the other hand, the authors have been open about the issues that the service has had to face, like managing the impact of behaviours on local neighbourhoods. The study tells us about the sorts of things that can help or stop a service from working well. The authors also acknowledge that this model needs to be evaluated.

Baker PA (2007) Individual and service factors affecting deinstitutionalization and community use of people with intellectual disabilities

Review question(s): 3.1

Organisations author involved with:

1. Sussex Partnership NHS Trust/Tizard Centre, University of Kent at Canterbury, Canterbury, UK

Type of study: Comparison evaluation

Country: England, UK

Population: Adults with severe/profound intellectual disabilities, 34 in the leaving hospital group and 28 already living in the community group

Quality score:-

Type of service: Moving into community living

Study aim

In this study the author looks at the effect of the closure of a small intellectual disability hospital on how people are involved in their community. It compares the community participation of the people who had just left hospital with that in a similar group who are already living in the community. The study also looked at factors that might have an effect on the community use of people with intellectual disabilities.

Findings

The authors found that people are not able to participate in the community without support. Having said that, not being in an institution was reported to be a big part of people being able to participate in their community. Participation in the community works better if people have clear plans that set out what they want to do and the time when this should happen. These were described as individually written ‘community access goals’ that set out the types of activity/contact as well as specific conditions and times when this is supposed to happen.

Things that helped with community participation

Having individually written community access goals helps with community participation. People with higher levels of adaptive behaviour were more likely to participate in their community.

Things that got in the way of community participation

Being in an institution.

Considerations

The study was only relevant to us in part. This is because the author notes that behaviour that challenges would be a factor that affected people’s community participation, but they don’t say how many participants in each group may have displayed behaviour that challenges at the start.

The design of the study was limited for a number of reasons. Some of the things measured, and linked to community participation, were very similar to each other. For example, the researcher used 2 different tools to measure behaviour that challenges – the Aberrant Behaviour Checklist and the Behaviour Problems Inventory. This might have affected the ability of the statistical model to explain the associations with community participation when looked at all together.

There may be some things which make a difference to whether or not a placement breaks down that have not been included in this study. From a small sample size it is difficult to know whether all factors have been identified, or whether the staff and people using the services included are similar to others.

Like many studies in this field, the sample size was small and only done in 1 area. As we see lots of variation in service provision in different areas, this might have affected people's ability to participate in their community according to what activities might be available in their area.

Balogh R, McMorris CA, Lunsky Y, Oulette-Kuntz H, Bourne L, Colantonio A, Goncalves-Bradley D (2016) Organising healthcare services for persons with an intellectual disability

Review question(s): 3.1

Organisations authors involved with:

1. Faculty of Health Sciences, University of Ontario Institute of Technology, Canada
2. Cumming School of Medicine, University of Calgary, Canada
3. Centre for Addiction and Mental Health, University of Toronto, Canada
4. Department of Public Health Sciences, Queen's University, Canada
5. Cancer Care Ontario, Toronto, Canada
6. Rehabilitation Sciences Institute, University of Toronto, Canada
7. Nuffield Department of Population Health, University of Oxford, Oxford, UK

Type of study: Cochrane systematic review. – the review included 7 randomised controlled trials (RCTs).

Country: International – 5 studies are from the UK, 1 from the USA, 1 from the Netherlands

Population: Adults with an intellectual disability and concurrent mental or behavioural problems (16 years and older), mainly in their 30s and early 40s, mainly male

Quality score: ++

Type of service: Assertive outreach, community-based specialist behaviour therapy, intensive case management

Study aim

The authors were interested in finding out if providing intensive community support services is better than providing health services to people with learning disabilities in the usual way (i.e. GP or community learning disability team in England).

Findings

The study included 7 RCTs. The sample size for included studies was small (range 20 to 63) with the exception of the study by Hassiotis (2001) (104 participants). The 7 RCTs were: Coelho (1993), Dowling (2006) Hassiotis (2001), Martin (2005), Oliver (2005), van Minnen (1997) and 1 new randomised controlled study (Hassiotis 2009). The authors also acknowledge a 2 year outcome update to the new randomised controlled trial by Hassiotis et al (Hassiotis 2011[10]). The 2 year outcome update was not included in the analysis as the groups were not randomised by the 2 year follow-up.

These are the most reliable kinds of study designs to know whether any differences between groups can be said to be caused by the intervention.

Four of the trials (200 participants) looked at what happened when you increased the intensity and frequency of service delivery (Coelho 1993; Hassiotis 2001; Martin 2005; Oliver 2005). One trial (63 participants) looked at community-based specialist behaviour therapy (Hassiotis 2009, 2011); 1 (34 participants) looked at traditional counselling and an integrated intervention for bereavement (Dowling 2006); and 1 looked at an assertive outreach service (van Minnen 1997) (50 participants).

Four of the studies measured behaviour problems as an outcome, 3 looked at the impact on carers and 3 looked at costs.

Overall, the study found that there is little evidence on how best to organise healthcare services for people with a learning disability.

Intensive community support: it is uncertain whether increasing the frequency and intensity of services decreases behavioural problems. Increasing the intensity of a

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[10] Hassiotis A, Canagasabey A, Robotham D, Marston L, Romeo R, Kin M. (2011) Applied behaviour analysis and standard treatment in intellectual disability: 2-year outcomes. British Journal of Psychiatry 198(6), 490-491

service probably makes little difference to the burden on carers and little to no difference to costs.

Assertive community outreach: it is uncertain whether outreach treatment compared to hospital treatment decreases behavioural problems or decreases the burden on carers. It is also uncertain whether outreach treatment decreases costs.

Community-based specialist behaviour therapy: there was evidence that this type of support may slightly decrease behavioural problems and may make no or little difference to costs.

Considerations

All the studies in the review were about adults with a learning disability and who had additional mental health or behaviour problems, which makes the findings relevant to our review. However, the severity of behaviour problems in the studies ranged from bereavement (Dowling 2006) to severe psychotic illness (Hassiotis 2001).

None of the included studies worked out how many people they would need to detect a statistically significant effect, so this means that even when pooling the data from the different studies, there may not be enough participants to detect an effect overall.

On the other hand, where there is no difference between types of services in terms outcomes or costs, this could also mean that the service is no worse than usual, so the decision between the 2 might be decided by the preferences of the people using the services. Standard or usual care that the interventions were compared to was usually service provided by community learning disability teams. Sometimes, when there is little or no difference between groups it can be because there is little difference in practice in the activities and components of the intervention and standard care.

Barron DA, Hassiotis A, Paschos D (2011) Out-of-area provision for adults with intellectual disabilities and challenging behaviour in England: policy perspectives and clinical reality

Review question(s): 3.1, additional economic analysis on housing

See narrative summary in section 3.1.

Beadle-Brown J, Hutchinson A, Whelton B (2008) A better life: the implementation and effect of person-centred active support in the Avenues Trust

Review question(s): 3.1

Organisations authors involved with:

1. Tizard Centre, University of Kent, Canterbury
2. The Avenues Trust, Sidcup, Kent

Type of study: Process evaluation of implementing person-centred active supports by a service provider

Country: UK

Population: Adults

Quality score: -

Background

This study looked at how person-centred active support was put in place by 1 organisation, the Avenues Trust. The trust tested active support in 6 services.

The researchers measured ‘active support activity’ before the approach was put in place and 1 year after. That way you could see the effect the introduction of active support had on the people living in the test services, and the staff working in those services.

The researchers measured 2 main things:

1. The service users’ engagement or participation in daily activities.
2. Amount of staff contact and assistance to service users.

The researchers used a number of different tools to measure active support. The tools and checklists used are all ones that are well used and have been tested by others.

To be able to complete the checklists, the researchers observed the service users usually over a 2-hour period between 16.00 and 18.00 in the lead-up to the evening meal, to allow as many opportunities for participation in activity as possible.

The researcher taking the observations was trained and experienced and not connected with the Avenues Trust in any way.

Findings

Engagement in meaningful activities

The amount of time people spent engaged in any meaningful activity nearly doubled.

Social interaction or support

There was a 300% increase in the amount of facilitative assistance provided by staff.

There was a significant increase in the quality of staff support as measured by the Active Support Measure. Mean percentage score on active support increased significantly ($p<0.001$) from 33% (range 17–54) to 64% (range 25 to 93), a 94% increase in active support.

There were significant increases in the ratings for individual planning, activity planning, support for resident activity.

Behaviour that challenges

There was a 53% decrease in self-injurious behaviour from 0.36 to 0.17% of the time. There was a reduction in stereotypic and repetitive behaviours from 21 to 16%.

Staff satisfaction

Staff reported higher levels of satisfaction, higher quality of management and more practice leadership from their managers after the implementation. The percentage of staff reporting that their manager usually modelled good practice increased from 42 to 78% and the percentage reporting that managers usually gave feedback almost doubled from 48 to 81%.

After the implementation, 96% of staff reported that they were at least quite satisfied overall (increasing from 77% before). In addition, staff wanting to leave in the next 12 months decreased from 34 to 10% of staff.

Choice and control

Opportunities for choice increased significantly ($p<0.05$).

Participation in daily life

There was a significant increase in participation in daily life ($p<0.01$).

Considerations

The researchers conclude that the implementation has been successful in the Avenues Trust overall. However, the trust takes care of more than 400 people with intellectual disabilities, and this study involved only 29 people. We do not know whether this group is representative of the residents of Avenues Trust homes overall.

There are some other concerns about the way the study was carried out which is why we rated it as poor. For example, there was only a short period for observations taken at the same time each day, but people may have had active support at different time periods in the day.

Staff questionnaires could not be matched between follow-up and baseline because most staff had refused to provide the identification code requested at the start.

There was also a high risk of bias from something called ‘the observer effect’. This means that people using support and staff were aware of the researcher watching them, and may have changed their behaviour.

The process of implementing person-centred active support and making it part of normal practice in an organisation is complex and requires dedication from all staff. It needs to be reviewed and adapted frequently to ensure maintenance and continued development.

There are some things that the study found that could help make implementation successful. Involving those in corporate and operational roles helped create a shared understanding of its importance at all levels of the organisation. Training trainers within the organisation ensures a greater degree of ownership and helps to get the message to services which have yet to be trained. Person-centred active support to be aligned with other person-centred approaches such as person-centred planning, positive behaviour support and total communication.

Beadle-Brown J, Mansell J, Cambridge P, Milne A, Whelton B (2010) Adult protection of people with intellectual disabilities: incidence, nature and responses

Review question(s): 1.1, 1.3, 3.2, additional economic analysis on housing

See narrative summary in section 3.1.

Bigby C, Beadle-Brown J (2016) Improving quality of life outcomes in supported accommodation for people with intellectual disability: what makes a difference?

Review question(s): 3.1, additional economic analysis on housing

See narrative summary in section 3.1.

Broadhurst S, Mansell J (2007) Organizational and individual factors associated with breakdown of residential placements for people with intellectual disabilities

Review question(s): 3.2

Organisations authors involved with:

1. Tizard Centre, University of Kent at Canterbury, Beverley Farm, Canterbury, UK

Type of study: Qualitative

Country: England, UK

Population: Interviews were with managers of care homes for people with intellectual disabilities – there were 19 people whose placement had broken down, and 20 people whose placement had been maintained

Quality score: +

Type of service: Residential placement

Study aim

This study was interested in people with intellectual disabilities whose behaviour challenges. The researchers wanted to find out whether there were differences between services, when comparing people who had placements break down with those who hadn't (the 'placement maintained' group).

Findings

Organisation and staffing

Homes in the placement maintained group had better written guidelines telling staff how to support people in the homes. The staff were also better supported by managers in supervision and team meetings. They also had training and coaching.

Staff contact/assistance

The placement maintained group staff said they had more support from people who did different jobs to them. People with different professional backgrounds advised them about how to help the people in the care homes.

Considerations

There were few differences between the 2 groups in terms of level of disability or behaviour that challenges. But the breakdown group had more residents who displayed sexually inappropriate behaviour than the group in maintained placements. The authors say that this may be that staff know less about how to deal with this, or they have a lower tolerance for this kind of behaviour and that's why the placement was more likely to break down. The placement breakdown group also were of a higher intellectual ability. Authors suggest that staff have higher expectations from more able residents and are less tolerant of behaviour that challenges, leading to a crisis and placement breakdown.

Study limitations

There may be some things which make a difference to whether or not a placement breaks down that have not been included in this study. From a small sample size it is difficult to know whether all factors have been identified, or that the people included are similar to people not included. However, the findings are supported by findings in other studies that staff and other organisational factors can affect how successful a placement will be.

Buxton L, Pidduck D, Marston G, Perry D (2004) Development of a multidisciplinary care pathway for a specialist learning disability inpatient treatment and assessment unit

Review question(s): 2.2, 3.1, 5.1

See narrative summary in section 3.2.

Challenging Behaviour Foundation (2015) Paving the way: how to develop effective local services for children with learning disabilities whose behaviours challenge

Review question(s): 3.1, 5.1

Type of study: Process evaluation

Country: UK

Population: Children

Quality score: -

Study aim

This study provides 5 good practice examples. These are from services that provide different kinds of positive behavioural support to children and young people and their families.

An overview of the 4 case study services included in the study:

1. Wolverhampton Special Needs Early Years Service

What it is: the service aims to assess, diagnose and offer early intervention for individual children aged from 0 to 5. They do this by putting the child at the centre of the care. A team of people from different organisations then work around the child. The team is led by a ‘key worker’ – someone who helps join things up.

What difference it makes: the findings suggest that it is person-focused care which can improve outcomes.

2. Coventry and Warwickshire Community Learning Disability

What it is: the service aims to provide ‘multidisciplinary support’ – that means support from professionals that have different skills to address different needs. In particular, they support children whose needs cannot be fully met by general health services. They do this through intensive child-focused, one-to-one support for families.

What difference it makes: the service is said to mean that few children have placements outside of their local area. For those children that do, the team will review progress and provide advice to the school they are in.

3. Stepping Stones in Brighton and Hove

What it is: the service provides parenting programmes that have been shown to work well – they are ‘evidence-based’. This is to give parents the skills and confidence to manage behaviour effectively.

What difference it makes: a ‘before-and-after’ evaluation has shown improvements in children’s behaviour, adults’ parenting skills and wellbeing.

4. Bristol Positive Behavioural Support Service

What it is: the service aims to build children’s skills so they can: be more independent; take part in social activities; have a better quality of life; and stay in school rather than having to move away from their local area.

What difference it makes: 12 children aged over 5 years old were supported in this way. As a result, they have improved their communication skills. Ten of the 12 children stayed permanently in their local school.

5. Ealing Intensive Therapeutic Short Break Service

What it is: the service aims to help the young person stay in their family home, and, longer-term, in their local area.

What difference it makes: almost all the children who have received the crisis intervention stayed in the community. Families were also able to cope better. This meant that the young person and their family had a better quality of life.

Findings

Things that worked well were working with parents – people working well together in teams led by parents or with a lot of involvement of parents in care planning (Brighton & Hove; Wolverhampton). When services are committed and patient – it is important to understand it takes time to help children develop new skills (Bristol; Ealing). When organisations work together so that all a child's needs can be addressed, and families don't have to tell the same story lots of times (Wolverhampton; Brighton & Hove). When staff have the right skills to use the approaches in question, for example, by writing this in their job descriptions (Wolverhampton; Bristol). When there is consistency across settings – for example, this could mean offering a parenting programme in settings that everyone uses so there is no stigma (Brighton & Hove). Or it could mean finding a way to make sure an approach is carried out at home and school (Bristol). Early intervention – it can be helpful when a person-centred approach is offered before children start school (Wolverhampton). When there is family support – looking after the emotional health of families can help then to cope better with their child's needs (Coventry and Warwickshire).

Things that worked less well

These were: not having the right knowledge and skills – for example, often professionals don't know enough about dealing with behaviour that challenges or mental health issues (Coventry and Warwickshire; Bristol; Ealing). Having an unhelpful organisational culture – for example, 1 where doing well in inspections is seen as more important than other things (Bristol); or where block contracts make it difficult to provide personalised services (Wolverhampton). People not being able to see there are different options for helping a child – parents may not realise that services other than residential schools can help. They may not want to take part in a particular service or learn new skills. (Coventry and Warwickshire; Ealing). Not knowing whether there is enough money to keep providing the service from 1 year to the next – it is hard for organisations to plan long-term when they don't know how much money they will be able to get in the future (Wolverhampton).

Considerations

We have included this process evaluation because it provides case studies that the Early Intervention Project, funded by the Department of Health and delivered jointly by the Challenging Behaviour Foundation and the Council for Disabled Children, think are good.

There wasn't a lot of information provided in the case studies about the quality of each evaluation so we have had to score them as poor. However the same sort of information is provided about each service.

The authors say that the interventions described in this paper are all underpinned by a sound evidence base: they have been proven to work and they represent a good investment, reducing the need for crisis interventions and residential placements and improving outcomes for children and families. However, the authors do not provide any research evidence or references to proper evaluations of each of the services considered for us to know.

The case studies give us an idea about the types of services that seem effective. We would need more research and evaluation to be done to know for sure whether they really are types of services to recommend. We cannot know that for sure from the information in these studies.

The case studies also tell us a bit about the sorts of things that can help or stop a service from working well. However, we need to remember that these things relate only to 1 or 2 local services.

Christopher R, Horsley S (2015) An evaluation of a behavioural support team for adults with a learning disability and behaviours that challenge from a multi-agency perspective (2015)

Review question(s): 3.1

Organisations authors involved with:

1. School of Psychology, University of Birmingham

2. Black Country Partnership Foundation Trust Ridge Hill Centre

Type of study: Qualitative process evaluation – the views and experiences of people working in the behaviour support team

Country: England, UK

Population: Health and social care providers

Quality score: +

Study aim

This study looked at whether the Dudley behaviour support team (BST) is meeting guidelines (Ensuring Quality Services, McGill 2013) set out by the government to ensure services are doing their job well.

The researchers looked at BST from the perspective of other services. That way they thought they could find out more about how the BST are working with service providers and social care. In particular, they wanted to find out how the positive behaviour support (PBS) pathway was working and to identify the team's strengths and areas for improvements.

To do this they collected the opinions of people who had experience of working with the BST. Nineteen staff members from independent service providers and social services were interviewed face-to-face using a structured questionnaire. A content analysis was used to explore themes within the qualitative responses.

Findings

This study found that the BST is meeting the government guidelines to a high standard. The response was 100% yes to 5 out of the 7 questions. For the remaining 2 questions, 1 about support to implement any changes and the other about advice given to monitor and evaluate any changes made in individual support plans, the responses were 84% and 68% respectively.

The qualitative responses helped to identify what was working well and where the team could improve. The things that helped the team achieve the standard include: a focus on joint working and inclusion of services throughout the assessment and intervention process (15 responses) (p7). A fluid, flexible approach to the needs of the client and service. This included listening rather than being prescriptive in the way the service was delivered and making reasonable adjustments for the client. The personal qualities of the team, such as being approachable, professional and respectful were also highlighted as important. Respondents also highlighted the amount of knowledge they had gained through working with the BST (7 responses) (p8): 'It was really good, I learnt a lot. It was a classic example of joint working' (private service provider manager) (p6).

One area, identified for improvement is that of monitoring and evaluating outcomes. The researchers noted that the team had already started to move towards a 'behaviour pathway'. This is more focused on measuring what happens as a result of separate parts of a person's support. For example, outcomes will be documented throughout the process of assessment, formulation and intervention. These outcomes will be measured at each point of the client's journey through the pathway, rather than just showing what happens when they stop using the service.

Considerations

The researchers also point to a potential issue when implementing monitoring of service outcomes of BST services. They say that activity monitoring on the basis of face-to-face contact with clients may be problematic for services such as the BST. Therefore, any activity monitoring systems for teams such as the BST need to take into account the complex nature of the work being done and allow the flexibility that has been identified as important by the services in this evaluation.

Study limitations

The researchers carried out the analysis well, followed good practice and took care to verify and test the reliability of the coding scheme they used. However, there are some concerns about other aspects of how the study was conducted that make the results less reliable, which is why we rated the quality of the study overall as 'moderate'.

For example, the participants self-selected to take part in the research, which may have created a bias in the results. Services may have been more willing to take part if they have a good relationship with the BST. Additionally, the questionnaire was conducted by a trainee clinical psychologist on placement within the service; potentially participants may have perceived her to be part of the BST and been less willing to give negative responses.

This study is of a single service in 1 geographic location. The participants volunteered to take part. This causes some 'positive bias' meaning we don't know whether there is any difference between those that chose to take part compared to those that didn't. It could be, for example, the people were more likely to take part if they had a good relationship with the BST.

We also don't know what proportion the sample size is to the total population of other services likely to come in contact with it or even the total size of service users. We therefore don't know that the findings related to this service would be what you would expect, or what you could use, elsewhere.

The researchers suggest that there are other ways that this type of evaluation could be improved. They said it would be better to take into account the views of service users and their families. And to include an audit of paperwork to evidence standards are being met.

Department of Health (2015) Securing inclusion and independence for all. Impact assessment

Review question(s): 3.2 (economic narrative summary)

Organisations authors are involved with:

1. Department of Health

2. Department of Communities and Local Government

3. NHS England

Type of study: Economic modelling study

Country: UK

Population: Individuals with learning disabilities in inpatient settings

Study aim

The Department of Health wanted to know whether providing personal health budgets to people with learning disabilities could improve people's outcomes. They also wanted to know whether it might reduce total costs to both social care services and the NHS.

Findings

Giving personal health budgets (PHB) to people with learning disabilities who are in inpatient settings might result in them moving to community settings much sooner. If this happens, £3.7 million pounds could be saved, over a 10-year period,[11] for both NHS and social care services, with most of the savings accruing to the NHS.

It is possible that people moving into the community would have better outcomes if people get better continuity of care and are reunited with family and friends. Having family and friends and therefore reducing social isolation reduces the chances of developing mental health problems and reduces the chance of dying sooner.

The analysis is based on the following data and assumptions:

(1) Cost of care package in an inpatient setting is £178,000 per year, which is based on national data collection.

(2) It is assumed that these individuals would move into fully staffed group homes in the community and would have average care package costs of £144,00 per year.

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[11] Costs are discounted at a 3.5% rate per year. Prices reflect the 2015 year.

(3) It is also assumed that individuals would move into the community 12 months sooner than if they were not provided with a personal health budget.

(4) The administrative costs of the personal health budgets are £4,300 per person per year and this is based on an assumption that 14 new individuals (3%) decide to use personal health budgets each year over the 10-year period. These administrative costs will decrease as more people use personal health budgets.

This analysis needs to be considered with a lot of caution because this is based on assumptions (based on their review of the research) and is not based on an actual evaluation of people with learning disabilities and behaviour that challenges.

There are 3 things that influence the impact on cost savings described above. The first is the cost of the community care package (assumed to be £144,000 per year), the second is the number of people that actually take a personal health budget each year (3%, or 14 new people per year), and third, how much sooner people leave hospital (assumed 12 months sooner).

If the cost of the community care package were higher than expected (£170,000 per year), then the savings would be smaller, at £1 million over a 10-year period. If the cost of community care package were lower than expected (£118,000 per year), then the savings would be larger, at £6.4 million over a 10-year period.

If the number of people who take personal health budgets were lower than expected (1%, 4 people per year), the cost savings is smaller, at £1.2 million over a 10-year period.

If people don’t leave the hospital as soon as expected (4 months sooner rather than 12 months), then the savings will be smaller, at £1.2 million over a 10-year period.

The cost of providing personal health budgets is included in the calculations above.

Taken together, the modelling exercise usefully demonstrates the potential impact on outcomes and costs if people were given personal health budgets.

The authors fully state their assumptions and appropriately test them with sensitivity analysis (as described in #4 above).

The sensitivity analysis indicates that even in ‘worst-case’ scenarios, there is, at minimum, likely to be cost-savings over a 10-year period.

This analysis is partly applicable the review question.

(1) The analysis makes assumptions about the impact on individuals with learning disabilities in inpatient settings. While they do not explicitly focus on those with challenging behaviour, it is very likely that these individuals do have challenging behaviour.

(2) The analysis assumes that individuals would move from inpatient settings and into fully staffed group homes. It is unclear whether this is an appropriate comparison group, especially as individuals might also move into supported living in a single-occupancy flat.

This is likely to increase the cost of the community care package. This would result in smaller net cost savings. However, these need to be considered alongside improvements in outcomes.

This is not to say that the analysis is inappropriate, but that there may be other settings that individuals move into and the analysis does not consider those scenarios.

Appropriateness of unit costs?

The unit costs of community care packages of fully staffed group homes are appropriate, they are based on PSSRU unit cost data. Unit costs for NHS inpatient services are appropriate, and are based on average national tariffs for an inpatient stay. The administrative costs of personal health budgets were also appropriate, based on bottom-up costing and used PSSRU unit cost data.[12]

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[12] https://www.phbe.org.uk/index-phbe.php.

Why this is important

In 2014, there were approximately 3230 people with learning disabilities in inpatient settings.[13] There has been very little progress in moving people from inpatient settings in to the community.

Devapriam J, Alexander R, Gumber R, Pither J, Gangadharan S. (2014) Impact of care pathway-based approach on outcomes in a specialist intellectual disability inpatient unit

Review question(s): 2.2, 3.1, 5.1, 5.2

See narrative summary in section 3.2.

Evans T, and Gore N. (2016) Staff behaviours valued by service users: views of people whose behaviour challenges

Review question(s): 3.3
Organisations authors involved with:
1. Southdown Housing, Sussex
2. Tizard Centre, University of Kent

Type of study: Qualitative, interviews of people's views

Country: England, UK

Population: People with mild to moderate learning disability and behaviour that challenges services

Quality score: +

Type of service: Community support service in the South of England

Study aim

To find out directly from people with a learning disability and behaviour that challenges what staff behaviours they like and don't like.

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[13] Estimates for 2014, Learning Disability Census.

Characteristics

Seventeen people took part in the study. They all had a mild to moderate learning disability and were described as presenting with behaviour that challenges. Ten were male and 7 female, median age = 40. They had all experienced a range of services in a range of settings and had lots of experience of having staff support them.

Findings

Interviews lasted around 15 minutes. All but 1 interview were recorded and the text was transcribed. The researchers looked for common patterns and themes in what people said about the things that they liked and didn't like about staff characteristics. They found 5 themes and 8 subthemes:

Theme 1. 'A nice person; a kind person'

All 17 of the participants said they valued support workers being nice or kind. Some people said that they also liked it when their support workers had a sense of humour or ability to make participants laugh, treating them 'in a good way', being 'caring', 'generous', 'honest', 'talkative'.

Subthemes

How staff speak

When staff spoke in a respectfully and in a calm way, this was valued by participants.

Interviewer: What do they do that upsets you?'

D: 'It's the way they speaks to people I don't like.'

Interviewer: 'How?'

D: 'This is it: [adopts loud voice] "D" like that. Aggressive. I don't like loud aggressive. I like calmly' (participant 13) (p7).

Friendliness

Participants valued friendliness in staff members, being unfriendly was when they were ‘taking the mickey’ or saying unkind things.

Theme 2. ‘Help me’

Fourteen of the 17 participants talked about help, being helped to do things, being helped when they could not do things themselves. Being looked out for or being looked after.

There were 3 subthemes that were related to this theme.

Subthemes

Practical help

Some people said it was the practical help they valued, and others said they did not get enough practical help from support staff.

Emotional support and feeling safe

Some people said that they valued it when support staff helped them with their emotional life, like if they had family problems. Sometimes this was making people safe and reassured.

Help when angry or upset

Some participants said what sort of support they needed if they were angry or upset. that support staff should be able to know what to do to calm them down.

Theme 3. ‘Not controlling of my life’

Ten participants talked about not being controlled by support staff. Some people were very annoyed when this happened, and some people seemed to feel there was nothing they could do about it. People who talked about this theme also said there was a difference between giving advice and trying to take over and be controlling.

‘They were good at giving advice, what to do what not to do, advice not telling’ (participant 6) (p8).

Three subthemes were also identified from this theme.

Subthemes

Being told what to do

Participants who said they did not like support staff controlling their life sometimes said that they did not like being rushed, or being told what they could and could not do, being bossy or nagging.

Being ‘told off’

When people talked about being told off, this was often felt to be unfair.

Service arrangements and rules

This theme emerged as about how staff approached service arrangements and rules. Some people said that the way staffing was arranged had nothing to do with their needs. Some people said that having too much staff support was intrusive and controlling.

‘Cos I’m independent, I wanna go in the real world, see my friends family, stuff like that really, but y’know, I don’t want it all the time but I like to be around people but I don’t need support all the time. It don’t get me anywhere’ (participant 7) (p8).

Theme 4. ‘Know me well’

Seven participants talked about how support workers should know them well. People have different preferences and routines, if support staff didn’t know or forgot this could cause upset and anxiety and behaviour that challenges. Another example was when the schedule for the next week didn’t say which support worker could be expected.

‘I always want to know who’s working with me. I wish they would sort it out’ (participant 17) (p9).

Theme 5. ‘Make time’

Participants said that they appreciated it when support staff made time for them, to talk or made time to be available to give support.

‘They spend time with me, they talk to me, make time, talk about things’ (participant 4) (p9).

But when staff didn’t make time, or seemed to busy, it made people feel less valued or important.

Considerations

The participants were all able to communicate verbally with the interviewer and generally had mild to moderate learning disability and so represent the views of a proportion of people with learning disabilities. We do not know if people who communicate differently or have more severe learning disabilities have different needs or value different things from their support staff. The people who took part were all from the same region of the country and receive services from the same providers so may not be representative to other areas and other providers. There may be agreement on themes that result from common experiences rather than the relative importance of the themes that were raised.

However, the interviews were well conducted and allowed time for people to speak. The researchers made sure that more than 1 persons’ interpretation of the views was in the analysis.

Griffith M, Hutchinson L, Hastings R (2013) ‘I'm not a patient, I'm a person’: The experiences of individuals with intellectual disabilities and challenging behaviour – a thematic synthesis of qualitative studies

Review question(s): 3.3

Organisations authors involved with:

1. School of Psychology, Bangor University.

2. University of Warwick, Coventry

Type of study: Systematic review of views

Study aim

The authors were interested in finding out what life was like for people who had intellectual disabilities and behaviour that challenges. They wanted to find out if there were common themes in the things that people said.

Findings

Choice and control. People talked about how little control they had over their lives. This could be something as simple as who can come into their room without asking. It could also be that people didn't listen to them, even when they were talking about something to do with them. They felt frustrated at not having enough choice and control. This is because they think it important to be treated as a person. They said they did not feel like they had any power. Other people had power but they didn't.

Causes of behaviour that challenges. People said that sometimes the places that are supposed to help with behaviour that challenges can actually cause it to happen. This could be because the environment is not very nice. People said that, in particular, secure residential units can feel scary and violent.

Staff behaviour. People in the studies said that they felt ignored by staff, even when they tried to talk to them. This could upset them and make them feel angry. They also thought that sometimes staff did not try to hide it when they felt in a bad mood. Staff could come across as rude, bad-tempered, too concerned about being seen as being in charge, or not bothered. When staff had good people skills, this was said to be helpful.

Trust. Sometimes people who lived in residential placements found it difficult to build trust with people. This made it extra difficult to get to know staff. This was made worse when there are lots of different staff leaving and starting all the time.

Considerations

This was a good study of views and experiences. The authors talked about how researchers bring their own views when they read what people say and try to make sense of it. They tried to address this by making sure that the decisions they made were shared in the group and decided on together. They also tried hard to make sure that the voices of the people taking part in the research is shown clearly. Most people who took part were in residential settings so this does limit the findings.

Griffith GM, Hastings RP (2014) 'He's hard work but he's worth it'. The experience of caregivers of individuals with intellectual disabilities and challenging behaviour: A meta-synthesis of qualitative research

Review question(s): 3.3

Organisations authors involved with:

1. School of Psychology, Bangor University, Bangor, UK

Study aim

The authors were interested to find out what life was like for people who cared for member of the family who had a learning disability and behaviour that was sometimes challenging. To do this, they looked at what people said in lots of different studies that asked carers what they thought about their life.

This is a good study as the authors are very clear about how and why they collected the other studies together, it is published quite recently and includes lots of people. So this means that it is quite likely it will reflect what life is really like for most people who care for a person with learning disabilities and behaviour that challenges (and not just a few).

They also were careful that they did not change the meaning of what people said in the studies and the authors often checked each other's work to make sure of this.

The authors collected 17 different studies together that all asked people who cared for a member of the family who had a learning disability and behaviour that was sometimes challenging what life was like for them.

Eleven studies from the UK, 4 from the USA, 1 from Canada and 1 from Norway. There were 391 people in the studies altogether. The studies did not always say how the carer was related to the member of the family, or if they were a man or a woman, but those that did often said that they were the mother. There was a wide age range of carers, who could be aged from 27 years old to 78 years old.

The studies asked people a series of questions about their life and experiences and how they felt, what they found easy and what they found hard. The authors then grouped together the different things that people said into similar types.

Findings

The things that carers most often talked about were about 1. Love, 2. Altered identities (or the ways a person can change over time), 3. Crisis management (or: what to do when things go really wrong!), 4. Support is not just about services, 5. The future.

Some of the things that carers said about services were:

Different services often did not work together to meet the needs of the carers and their families and there was a lack of information to help. It seemed like a never-ending fight to get the right services, the system of services seemed difficult to understand and confusing and no one seemed to be there to help them. Carers said it was often left up to them to do things and services were more likely to wait for something to happen instead of planning ahead. But when professionals were honest with them, showed real interest in them and planned ahead with them to try to solve problems before they happened, this was very much appreciated and made life a lot easier. Carers often thought that staff did not know how to care for their family member properly. Carers sometimes found that short breaks centres (called respite centres) had staff that did not know how to cope with behaviour that challenges properly, and this meant that carers couldn't have a proper break because the staff kept calling them for advice on what to do, or staff asked that the carers were always available to take a phone call, or they had to end their break early because the staff said they couldn't look after their family member after all, or carers couldn't have a break at a time that was good for them.

Short breaks were very important to carers as without them they were tired physically and emotionally, and could get lonely as they had no time to see friends and other family.

Carers worried about the future and the different services their relative would need as they got older and if they would be available when they needed them.

Hassiotis A, Guinn A, Tanzarella M, McCarthy J, Roy A (2015) Community-based services for people with intellectual disability and mental health problems: literature review and survey results

Review question(s): 3.1, 3.2

Organisations authors involved with:

1. University College London

2. Hertfordshire Partnership NHS Foundation Trust

3. East London NHS Foundation Trust

4. East London NHS Foundation Trust

5. Faculty of Psychiatry of Intellectual Disability, Royal College of Psychiatrists

Type of study: Mixed methods study

Country: UK

Population: Adults

Quality score: -

Type of service: Specialist community-based service

Study aim

This study summarises the current evidence on community service models for adults with intellectual disability and mental health, behaviour or forensic problems. It also includes community-based psychiatrists' views about these services.

Findings

'Outcome measures'

In this study, an 'outcome measure' means a tool or questionnaire that can be used by practitioners to gather information about people's health or wellbeing in a consistent way. Practitioners said they do not use outcome measures routinely in their work. When they do, though, they most often use 1 called the ‘Health of the Nation Outcome Scales for People with Learning Disabilities’. The second most commonly used outcome measure is called the ‘Aberrant Behaviour Checklist’.

Service model

Most practitioners were able to say that their service was organised in a particular way – that is to say, they followed 1 ‘service model’. There were 4 particular service models that stood out as being most commonly used.

The most common model for community intellectual disability teams was the generic community intellectual disability team; 84% of people answering the survey said their service is structured in this way.

The next most common model was having specialist challenging behaviour services; 21.5% of people answering the survey said this was how things were organised where they work.

Stand-alone mental health intellectual disability teams were used by 16% of practitioners answering the survey.

Another 16% of practitioners said they have neurodevelopmental disorders services.

How to make things better

The practitioners who answered the survey said that to make things better in their areas, it would be good if there were more intensive support teams and different organisations worked together better; it was easier to link with ‘mainstream’ mental health services, that is to say those that are not specific to people with learning disabilities. They also thought it would be good if mainstream mental health services understood more about learning disabilities. If community services were better able to support people who may have previously been supported in hospital.

Joining up with other services

Less than half the practitioners answering the survey – 26 people – knew about local care pathways. Generally, practitioners said that their services were not linked in well with social care, apart from in London.

Most practitioners said their services were linked with mainstream mental health services in some way.

The survey findings suggest that community-based services are important for supporting people with intellectual disability in their homes. However, the results also suggest that there are not enough of these services and that, outside of London, they do not link up with other services well enough. The study suggests that there is more research needed into what the ideal community service should include, particularly to make sure it is personalised, effective and safe.

Considerations

The study was relevant to us; it looked at some things that help us answer the questions we have asked. The study focuses on ‘community-based intellectual disability services for people with mental health, behaviour and forensic problems’. It is not specifically about the population of people with learning disabilities and behaviours that challenge. However, these are services that we are interested in for our work, and some people with learning disabilities and behaviour that challenges may well use them.

The design of the study was limited because experts by experience were not involved. Some of the way that the survey reports methods and results is also not clear. This means it can be hard to make sense of some of the results. Also only a small number of practitioners were involved. This means that we cannot be very confident that the things they found in the survey apply to the whole of England.

Hassiotis A, Robotham D, Canagasabey A, Romeo R, Langridge D, Blizard R, Murad S, King M (2009) Randomized, single-blind, controlled trial of a specialist behavior therapy team for challenging behavior in adults with intellectual disabilities

Review question(s): 3.2

Organisations authors involved with: Department of Mental Health Sciences, University College London Medical School.

Study design: randomised, single-blind controlled trial

Country: UK

Population: Adults with intellectual disabilities and challenging behaviour

Quality: +

Aims

To test the effectiveness and cost-effectiveness of a community-based specialist behaviour therapy team (using applied behavioural analysis) plus standard treatment compared to standard treatment alone for adults with intellectual disabilities and challenging behaviour.

Methods

This is a randomised, single blind, control trial. The trial was carried out between 2005 and 2008 in South Essex (Greater London).

Recruitment was based on referred services users from community intellectual disability teams, and potential participants were screened for inclusion. Inclusion criteria were: participants with challenging behaviour severe enough that the individual was at risk of a placement breakdown or putting other individuals at risk.

Participants were excluded if challenging behaviour was a result of mental health problems, but the authors note that they assumed all patients may be comorbid with mental health problems.

The primary outcome measure was challenging behaviour, measured by the Aberrant Behaviour Checklist. Secondary outcome measures include psychiatric comorbidity, assessed with the Psychiatric Assessment Schedule for Adults with a Developmental Disability Checklist (PAS-ADD), and service use in the past 6 months, using the Client Service Receipt Inventory. Assessments were measured 3 times: before randomization, 3 months, and 6 months (end of trial). Costs were measured at the end of the 6 months, with service use reported for the past 6 months. Baseline service use was not measured so analyses are not able to adjust for previous service use.

Costs were calculated according to ‘treatment’ and ‘non-treatment’ costs (such as non-psychiatric inpatient stays, outpatient appointments, day care, leisure activities, adult education, support for voluntary work, and contact with general practitioners and other professionals, such as community nurse, social worker and advocate) (p1281). Costs to the criminal justice system and costs of informal care were not measured.

Findings

N=63 participants took part out of an eligible n=69. Sample was mostly white (95%), male (58.7%), and 66% had mild/moderate learning disabilities and the remainder had severe/profound learning disabilities. Attrition was low; 1 participant each died in the intervention and control arms and 1 participant in the intervention arm declined to participate in follow-up assessments.

Outcomes

The results of the study found that the intervention group did better than the standard treatment group on improvements in challenging behaviour (total scores on the Aberrant Behaviour Checklist), lethargy and hyperactivity subscale scores, and were less likely to have comorbid organic disorder.

Costs

At 6 months, there were no differences in health and social care service use/costs (including the costs of the intervention), although the intervention group was trending towards lower service use/costs.

Conclusion

In conclusion, at 6 months, the intervention group had better outcomes with no statistically significant differences in costs (even after including costs of the intervention), compared to the control group.

Considerations

The strengths of the study are:

(1) its pragmatic design, closely following clinical realities,

(2) very low attrition rate, n=3/63, and

(3) high model fidelity (the intervention being delivered as it was meant to be).

The limitations of the study are:

(1) the time horizon of the analysis was short, at 6 months – this was due to ethical constraints, as the control group are put on a waiting list to receive the intervention,

(2) small sample size meant that it was not possible to measure whether there were any interactions between severity of intellectual disability and outcome, and

(3) the time horizon may be too short in order to detect the full changes in service use, which we might expect due to better results for the intervention group on both challenging behaviour and mental health.

The authors say that the study has good external validity in relation to:

recruitment criteria being broad,

sample had similar levels of psychiatric comorbidities as found in large administrative samples.

However, external validity is unclear in relation to 'standard care.' In this study, 'standard care' comprised very few clinical psychologists, which means that the study participants were unlikely to have had psychological treatment before entering this study. The implication is that differences in standard care might change the results of the study, but the direction of that change is not known.

Hatton C, Emerson E, Kirby S, Kotwal H, Baines S, Hutchinson C, Dobson C Marks B (2010) Majority and minority ethnic family carers of adults with intellectual disabilities: Perceptions of challenging behaviour and family impact

Review question(s): 3.3

Organisations the authors are involved with:

1. Centre for Disability Research, Lancaster University, Lancaster, UK

2. NHS Central Lancashire, Preston, UK

Type of study: Qualitative – carers' experiences of existing services

Country: UK

Population: Majority and minority ethnic family carers of adults

Quality score: ++

Study aim

The study wanted to understand what family carers thought about what causes behaviour that challenges and what it could mean. They wanted to understand how the behaviour affected the family. They also wanted to know what help they got and what they would like. They wanted to know about families from different ethnic groups.

Findings

Access to support. Many families said it was really hard to get help from services and keep getting this help over time. Services were often not delivered for long enough, or were not flexible enough, or weren't the right ones. There were lots of changes to staff and to the way that things were done. These were not good for families. It made them feel frustrated and uncertain.

Asking for help. Some people from minority ethnic groups found it difficult to ask for help from within their own community.

Defining behaviour that challenges. Families said that behaviour that challenges is only 1 part of behaviour that causes problems. Lots of other types can be difficult for them and can cause problems for family life.

Carers' health and wellbeing. Carers were often not well. They were very worried about the future. They felt trapped because they had a member of their family who relied on them completely. Lots also felt lonely although some got help from neighbours, friends and other family members. This could be emotional support or help to actually do things – both were very useful and important. Where people had this help, it could make them feel better about things.

Respite care. Family carers found this very helpful.

Staff skills. People thought it was important that staff have the right skills and knowledge to help. This also affects how good the care is. It is a problem when staff are off sick and no one else steps in to help, or when people have to work with different staff who don't know them. It can be hard for people to build trust in staff and in organisations.

Considerations

This study is relevant to us because it looks at the views and experiences of how families function and how families can be effectively supported. The design of the study is limited because only a small number of people from minority ethnic communities are involved. It was also done in 1 local area so you will need to think about whether these findings are also likely to be relevant to other areas and different groups of people.

Iemmi V, Knapp M, Saville M, McWade P, McLennan K, Toogood S (2015) Positive behavioural support for adults with intellectual disabilities and behaviour that challenges: An initial exploration of the economic case

Review question(s): 3.2

Organisations authors involved with:

1. London School of Economics and Political Science, Personal Social Services Research Unit, London

2. Positive Behaviour Support Service, Halton Borough Council, UK

3. Bangor University, School of Psychology, Wales

Study design: economic modelling

Country: UK

Population: adults with intellectual disabilities and behaviour that challenges

Background and aims

This is an English economic modelling study. It aims to explore the economic case for positive behavioural support.

The analysis looks at n=5 male adults with intellectual disabilities and behaviour that challenges who either live alone (n=1), with parents (n=2), in supported housing (n=1), or in a nursing home (n=1). The economic model is composed of several parts. The study was conducted between 2010 and 2013.

The first part looks at the impact of a positive behavioural support service (PBS) on n=5 individuals. It measures the impact on 4 outcomes before and after PBS. Outcomes include behaviours that challenge (frequency and severity), activity engagement, and community participation. The outcomes are measured over a 6-month period.

The second part of the analysis looks at the impact of PBS on n=3 individual's use of health and social care service. Service use is measured over the first 6 months of receiving PBS.

The third part of the analysis is to estimate the hypothetical use of health and social care services if PBS were not provided. The purpose of that exercise was to try and create a hypothetical comparison group. These estimates were obtained using a group of experts. Experts were provided with 2 case studies of individuals who have different levels of need.

Findings on outcomes

The n=5 individuals either had made improvements in various outcomes over the 6-month period. No outcomes were worsened. For the 6-month period when individuals were receiving PBS, net costs to health and social care (inclusive of intervention costs) were increased by £225/week or £5,580/6 months.

In the short term (6 months), PBS is estimated to cost more but could deliver better outcomes. It is likely to be cost-effective. However, the authors believe that in the short and long term there could be reductions in the costs to individuals' informal carers.

From the view of public sector services, in the long-term, there is the potential for there to be cost savings, but it is unclear.

Considerations

This analysis is applicable but the quality of the analysis, due to the type of data used and design, has potentially serious limitations. The results are promising but more research is needed. Outcomes that were not measured but would have been beneficial include choice, control, engagement, independence, confidence etc. If individuals were receiving improved care packages, then it would be worth investigating whether these important social care outcomes were changed.

A longer time horizon would be advisable to investigate the impact on the use of inpatient and crises services as well as measured and unmeasured outcomes as a result of changes in their care package

Iemmi V, Knapp M, Jackson Brown F (2016) Positive behavioural support in schools for children and adolescents with intellectual disabilities whose behaviour challenges

Review question(s): 3.2

Organisations authors involved with:

1. London School of Economics and Political Science, Personal Social Services Research Unit, London

2. North Bristol NHS Trust, UK

Study design: economic modelling study

Country: UK

Population: children and adolescents with intellectual disabilities whose behaviour challenges

Background and aims

This is an English economic modelling study that aims to explore the economic case for positive behavioural support for children and adolescents at risk of residential education placement who have intellectual disabilities and behaviour that challenges. . Most were boys. Mean age was 10 years old (range =4–13). Most were white. All n=12 children attended public sector day school and received support from a classroom assistant (daily). N=11 children lived in the community and 1 lived in a care home. The study was conducted in 2009.

Method of analysis

The first part looks at the impact of a positive behavioural support service in schools (PBS) on n=12 children and adolescents. It measures the impact on 2 outcomes before and after PBS. Outcomes include the average number of behaviours that challenge per week and the Verbal Behaviour Milestones Assessment and Placement Program (VB-MAPP), which measures skills.

The outcomes are measured before and after the intervention (average duration of 22 months, range 7–42); n=9 individuals were used for analysis of challenging behaviour; n=5 individuals were used for analysis of VB-MAPP.

The second part of the analysis looks at the impact of PBS on n=12 individual's use of education, health and social care service and its impact on their carers. Service use is measured over the first 6 months of receiving PBS.

The third part of the analysis is to estimate the hypothetical use of education, health and social care services if PBS were not provided. The purpose of that exercise was to try and create a hypothetical comparison group. These estimates were obtained using a group of experts. Experts were provided with 4 case studies of individuals who have different levels of need.

Findings

The n=9 individuals reduced the average number of challenging behaviours per week when compared before and after receiving PBS support.

Before: 21 per week (sd=20, range 5–65)

After: 4 per week (sd=5, range 0–14)

The n=5 individuals improved on the Verbal Behaviour Milestones Assessment and Placement Program (VB-MAPP).

Before: 28 (sd=27, range 6–72)

After: 53 (sd=48, range 23–136)

Findings on costs

Intervention group: for the 6-month period when individuals were receiving PBS, net costs to the public sector were £1909.10 per week. (Includes education, health and social care and costs of PBS.) Additional costs to carers were £42.10 per week.

Cost of PBS intervention, £700.10 per week

Education, health, and social care, £1209 per week

Education =43%, £526 per week

Health and social care =56%, £683 per week

Comparison group: the experts were given 4 case studies of individuals with different levels of needs. This group estimated the weekly costs to education, health, and social services to be £762, £988, £1,336 and £1,440.

Conclusions

In the short term the impact on costs is not clear. The costs of PBS children were in the middle of the range in comparison to the examples provided in the 4 case studies. It is assumed that individuals who do not receive PBS will not have these benefits. It is likely that PBS is cost-effective. However we do not know for sure due to the study design.

Considerations

This analysis is applicable but the quality of the analysis, due to the type of data used and design, has potentially serious limitations. More research is needed to ensure that results are not biased and that results are generalisable. A longer time horizon would be advisable. There may have been long term cost savings with PBS.

Of the n=12 individuals at risk for residential education, only 2 were transferred to residential school. Another 3 individuals were still receiving ongoing PBS support.

Inchley-Mort S, Hassiotis A (2014) Complex behaviour service: content analysis of stakeholder opinions

Review question(s): 3.3

Organisations authors involved with:

1. Camden Learning Disabilities Service, Camden & Islington NHS Foundation Trust

2. Mental Health Sciences Unit, University College London

Type of study: Qualitative

Country: England, UK

Population: Adults with learning disabilities and behaviour that challenges

Quality score: ++

Type of service: Enhanced positive behaviour support

Study aim

To find out what service users and carers think of a complex behaviour service (CBS), based on positive behaviour support principles.

Findings

Overall both the carers/informants and service users said they were satisfied with the service despite a small number of negative comments about the CBS. Positive experiences of the service were linked to:

talking and listening in a way that made the person feel heard, carers feeling that their ideas and ways of working were requested, heard and utilised by the service,

the CBS allowing for challenging behaviours to be understood, interpreted and explained in a way that was meaningful to paid carers,

the level and response of contact with the CBS,

in-depth analysis of behaviours and discussion with wider networks.

Negative experiences of the service were linked to:

Involvement or engagement with the CBS ending too soon:

‘We would have liked longer input’ (support worker, 28) (p233).

‘[…] since the guidelines were put into place the person from the CBS has not been around as much’ (manager, 24) (p233).

Carers expectations of the service, which they had linked with severity of the challenging behaviour displayed:

‘[…] I was probably expecting a lot more. I do understand the fact that the service user’s behaviours are not bad […] and therefore he wasn’t given priority’ (care manager, 40) (p234).

In terms of impact of the service, the majority of people in the study reported improvement in behaviours and quality of life even in the absence of an obvious decrease in behaviour difficulties.

Considerations

This study was relevant to us. Although having the service for longer was said to be something good, it may be unsustainable in the long term, and isn’t really what positive behaviour support is for. One thing that could make the service work better was having shortened versions of the behavioural guidelines. These could be consulted in emergencies or at handover times. The positive and negative experiences of care, listed above, reflect what service users and carers say about what they like and don't like about the positive behaviour support service. These could be considered by service providers when they design services for people with learning disabilities and behaviours that challenge in the future.

The authors point out that while the need for service user and carer involvement in service development and evaluation has been widely recognised (Bonell et al. 2011) and reflected in government policy (for example, Department of Health 2004; Scottish Executive 2006), it may not be feasible to include this level of service user and stakeholder consultation when implementing new services or interventions. However, it may be that some of the findings will be useful for, and relevant to, other services for people with the same needs.

The design of the study was limited for a number of reasons. While this study tells us about some of the things that help the service work better from the perspective of the service users and carers, it is not particularly specific. It doesn't identify exact things related to, for example, out of hours availability, or the level of behaviour severity that can be safely treated in the community. Knowing these things too could be useful for people planning and delivering services.

It is also worth noting that only a small number of people were involved in the study. We do not know if the findings are also relevant to other people involved in providing this sort of support, or other people using it.

The authors also describe how the study could be limited if people involved did not feel able to be critical of the service. This is because in 2 of the interviews with service users, the service users agreed that their support worker stayed in the room during the interview. They may not have said the same things in front of their support worker as they would have done if they had taken part in the interview alone. Also, another service user spoke freely prior to the formally recorded interview but he spoke less and answered ‘I don’t know’ to questions that he had previously answered differently once the recording of the interview had begun. However the researchers were careful and tried to reduce any potential bias by the interviewer by including a final question inviting participants to discuss anything they thought had been missed. They also used 2 additional researchers, independent of the project, in the work to analyse the issues and themes coming out of the interviews.

Inchley-Mort S, Rantell K, Wahlich C, Hassiotis A (2014) Complex behaviour service: enhanced model for challenging behaviour

Review question(s): 3.3

Organisations authors involved with:

1. Camden Learning Disabilities Service, Camden & Islington NHS

Foundation Trust, London, UK

2. JRO Communications, Joint Research Office (Part of the Research Support Centre), University College London, London, UK

3. Mental Health Sciences Unit, University College London, London, UK

Study design: matched comparison study, qualitative study

Country: UK

Population: adults with intellectual disabilities and behaviour that challenges

Quality: ++ (qualitative study)

This study analyses the effects of a complex behaviour service (CBS) provided to n=24 adults, mainly male, aged 18+.

Methods of analysis

This is an observational study of n=22 people receiving CBS. They are then compared to n=24 adults, identified through the service register, who did not receive CBS. It was a matched comparison based on gender, level of intellectual disability and level of challenging behaviour. They were compared over a 1-year period.

The authors wanted to see whether CBS would improve individuals' outcomes. The primary outcome was reducing challenging behaviour as measured by the Aberrant Behaviour Checklist (ABC). The secondary outcomes include mental and social functioning, met and unmet needs and mental health status.

The results are also adjusted to consider other individual characteristics that may influence results, including living situation, mental health problems, met and unmet needs and physical problems.

Findings

For the primary outcome, at 6 months, the CBS group had significantly reduced challenging behaviour in relation to the:

total score -11.8 (95% CI, 0 to 23.6),

domains of irritability -4.7 (95% CI, 0.6 to 8.8),

domains of stereotypy -2.0 (95% CI, 0.4 to 3.7).

the other domains were not different between groups: lethargy, hyperactivity, and inappropriate speech.

For the primary outcome at 12 months, the only remaining difference between groups was:

reduced challenging behaviour as measured by the stereotypy domain

For the secondary outcomes, there were no differences between groups at 12 months.

The analysis takes a very limited perspective on costs. The analysis only compares the differences in social care service costs, as measured by changes in care packages. The analysis does not include the operating costs of the intervention, that is, the ‘complex behaviour service’. The analysis does not include the impact on the use of NHS service. It also does not measure the impact on carers (costs or outcomes).

The authors found that the intervention group had higher social care package costs at the end of the 12-month period compared to the comparison group (approximately £604 increase per person per week). At baseline, intervention and control group average care package costs per week were similar. Intervention £972 (sd=£1,065). Comparison £1,017 (sd=£713).

12 months later, the intervention had higher social care package costs £1,468 (sd=£1,538) compared to the comparison group, £864 (sd= £712).

Actual costs to social care services might be higher than reported in this study because the authors did not include costs of the intervention. The intervention was provided by 2 full-time clinical psychologists and 1 full-time psychology graduate. Conclusion

Based on the limitations of the study it is not possible to come to a firm conclusion about the intervention's cost-effectiveness. However, it is possible that the intervention is cost-effective. he CBS group had improved outcomes at 6 and 12 months, with greater gains at 6 months and fewer gains at 12 months. In the short term costs are likely to increase to NHS and social care. In the short-term, as reported in the 12-month period of the study, costs are likely to increase to NHS & social care. Considerations

It would have been worth exploring other effects on individuals, such as feelings of choice, control, independence, and other social-care related measures of quality of life. It would have been useful to explore the impact on NHS service use and to include a longer time horizon. The CBS group had reduced challenging behaviour and changes in social care packages might reduce related crises and crisis-related service use.

James N (2013) The formal support experiences of family carers of people with an intellectual disability who also display challenging behaviour and/or mental health issues: what do carers say?

Review question(s): 3.3

Organisations authors involved with:

1. University of Glamorgan, UK

Study aim

The authors were interested to find out what life was like for people who cared for member of the family who had a learning disability and behaviour that was sometimes challenging, especially when it came to using different services.

This is a fairly good review as it is relevant to this guideline as it is about asking carers about their experiences of using services, It uses different studies than the Griffith (2014) review so includes the views and experiences of a different set of people, but it is the work of only 1 person so it only has that person's view of what the carers meant and there are not very many direct quotes from the carers themselves.

In total, the author gathered information from 17 different studies that included more than 2706 carers (sometimes the studies did not say how many people took part). These studies all asked people who cared for a member of the family who had a learning disability and behaviour that was sometimes challenging what life was like for them.

Findings

The authors put all the things that people said together. The things that carers most often talked about are below.

Looking for and getting help from services

Carers sometimes felt that it was too difficult to look after their family member properly and without support they could sometimes feel that the best place to be was out of the home to access more specialist care. When looking for specialist help carers often said that they most wanted training and advice on how to best cope themselves with difficult situations. Carers said that they were not getting the help they needed in practical ways and emotional help for themselves and the person they were caring for.

Carers often worried about the future for their children with learning disabilities and behaviour that challenges, especially as they grew up and needed different services. Carers often did not look for extra help as they thought the difficult situation would not last long but also that they didn't know where to look for the right help.

What stops carers getting the help they need?

Carers reported that difficult situations had to get very bad before different, more suitable services were offered. Services were not available when they were needed, or were not suitable for that particular person or didn't take into account the effect on the whole family. Carers felt that some professionals didn't know how to care for their family member properly.

Information

Carers found that when help was given to help cope with behaviour that challenges themselves they found this reduced stress and made them feel more able to cope in the future. They wanted professionals to take the time to explain information clearly, otherwise this caused confusion and stress. Sometimes carers felt they had to 'shout' to be heard.

La Valle I (2015) Services for children with learning disabilities whose behaviours challenge: A survey of families' and professionals' experiences

Review question(s): 3.3

Organisations the author was involved with: Visiting scholar at the University of East London

Type of study: Qualitative

Country: UK

Population: The people taking part in the study were parents/carers and professionals who work with children; the people using the services the study is about were children with learning disabilities and behaviour that challenges

Type of service: Support services for families and services for children with learning disabilities whose behaviour challenges

Quality score: -

Study aim

The study aimed to find out how much families and professionals know about support available for children with learning disabilities whose behaviour challenges. It also wanted to find out about how they access these services and what difficulties they face.

Findings

Which services families use, and what they think about them

Types of support used. Most of the families who were able to access support thought that support was good. The children of the parents in the study got different types of support. The number in brackets below tells you the percentage[14] of parents surveyed who said their children got this type of support.

- Special educational provision (84%)
- Speech and language therapy (73%)
- Occupational therapy (56%)
- Social services support (41%)
- CAMHS (24%)
- Physiotherapy (22%)
- Specialist behaviour support. Total 39% of children did not get specialist behaviour support. Of the children that did, about half got this in some type of school. The rest got it at home or somewhere else.

Getting support. The figures above show that some services are not used by many children. However, it may not simply be that people do not want or need them. Families in this study found it hard to access the support or advice they need to help their children. It was also often the case that children getting help are older, even though behaviour that challenges often starts in early childhood. They gave a long list of different examples of the different types of support they thought would help their child. Personal budgets were not always useful because there aren't the right services available for people to buy.

Where support is provided. Parents and carers were unhappy about not having enough home-based support. They thought this was very important for understanding and dealing with behaviour that challenges. Some parents thought that residential schools were not nice places for children to be and were too far

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[14] The word 'percentage' is a mathematical term. It just means 'in every hundred' of something. Look at the bullet point highlighted yellow as an example. This means that if we asked 100 parents like the ones in our survey whether their children had 'special educational provision', we would expect 84 to say they did.

away. They also thought that parent training would be better if it was done at home, because this is where they spend most time normally.

Information. Less than half the parents were provided with information and advice. When they did get information, most parents found it useful. When the survey asked what extra support they would like, a lot of people said they want more information about, and understanding of what families go through.

Professionals skills and knowledge. Parents said that professionals often do not have the right skills to support children with learning disabilities whose behaviour challenges. They also said that some key workers are not experienced, and then leave and are not replaced.

Respite care. Most parents thought respite care was not good enough. The quality was said to be poor and it was sometimes not in their local area.

What professionals think about services

Professionals thought the main different types of support, such as training for parents, short breaks and PBS worked very well. However, they did not think this about residential care; just over a third of the professionals involved in the study thought residential care rarely or never worked well. They also thought there were big ‘gaps’ in support in their local area – this means that not everything that is needed for support to be consistent is there.

Staff skills. Most professionals (76%) thought that the training they got to work with children with learning disabilities whose behaviour challenges was not good enough. They thought that it would make a big difference if people organising and providing services for children with learning disabilities and behaviour that challenges knew more about their needs.

Moving between services. Only a small amount of professionals said that ‘pathways’ between health, social care and education were in place for children with learning disabilities and behaviour that challenges of different ages. Related to this, they thought more should be done to plan services so they work together well and so that people do things in the same way.

What support works best. Professionals thought that the most useful type of support was regular physical health checks; regular sensory assessments; parent training; and positive behavioural support.

Working with families. Professionals thought that advocacy – having someone who can help you say what you want and act on your behalf – would make a big difference to children and their parents.

Considerations

This study was relevant to us. It looked at things that help us answer the questions we have asked. However, the design of the study was not very good. This was for a number of reasons.

Participants self-selected to take part, so their views may not be representative of those of parents or professionals who chose not to take part. We also do not know much about the people who did not complete the survey.

It also isn't very clear how the researchers organised the information and picked out the themes.

We should think carefully about how we make sense of the findings of this study.

Mansell J, Beadle-Brown J, Whelton B, Beckett C, Hutchinson A (2008) Effect of service structure and organization on staff care practices in small community homes for people with intellectual disabilities

Review question(s): 3.1

Organisations the authors were involved with:

1. Tizard Centre at the University of Kent

2. The Avenues Trust, Sidcup, Kent

Type of study: Comparison evaluation

Country: UK

Population: People

Quality score +

This study looked at the effect of a wide range of things relevant to organisations (that had already been investigated) on the extent of active support in community-based residential services.

The researchers wanted to know what types of staff care practices and organisation effected the way active support is provided.

Active support is an approach to providing direct help to people with learning disabilities so they can participate as fully as possible in daily activities.

The researchers compared active support in residential homes that had training on person centred active support (PCAS) and those who had not. There were 36 residential homes in the intervention group and 36 residential homes in the comparison group serving 359 adults with intellectual disabilities and with 354 staff.

The homes which would take part in the study were selected by the charity running the homes. They said they chose homes to ensure all geographical regions the charity served were covered; however, the sample may be biased, for example, if the charity felt that some homes would perform better or benefit more from the training.

The researchers used a number of different tools to measure active support. The tools and checklists used are all ones that are well used and have been tested by others. However, staff characteristics, experience and satisfaction was assessed using the Staff Experience and Satisfaction Questionnaire (LD) (Beadle-Brown et al. 2003) developed for use in this study.

Total 230 full questionnaires were returned from a total of 546 questionnaires sent out (a return rate of 42%). There were no significant differences between services where staff questionnaires were returned and those where none were returned in terms of size of home, staff:resident ratio, resident’s adaptive behaviour or challenging behaviour.

Each home was visited in order to observe the way staff provided support to residents. Observations were made over an approximate 2-hour period around a meal time because this seemed likely to provide many opportunities to see staff providing support.

Once data was collected about the residents of the 2 groups it appeared that they were comparable in terms of their age, adaptive behaviour, social impairment, gender and ethnicity. In terms of challenging behaviour, the groups were comparable in terms of Aberrant Behaviour Checklist (ABC) Factors 1–4 but the comparison group had a significantly higher average score on Factor 5 (inappropriate speech).

The researchers used a type of statistical analysis called ‘multivariate analysis’. They did this to try and find out which particular things are related to engagement and active support.

Staffing

There were no significant differences between the groups in terms of staff:resident ratio or the proportion of senior staff in the team. The PCAS group had significantly more staff with a professional qualification (z=4.145, p<0.001). Staff in the comparison group tended to attribute challenging behaviour to negative learnt behaviour explanations more than the PCAS group (z=2.753, p<0.01), while those in the PCAS group tended to attribute challenging behaviour to the need for stimulation more than the control group (z=2.416, p<0.05). Staff in the comparison group were more satisfied with their job (z=3.663, p<0.001). The PCAS group had attitudes significantly more in line with a policy of community care and empowerment for people with intellectual disabilities (z=3.880, p<0.001).

Findings

Active support

The PCAS group showed significantly higher implementation of active support, higher levels of assistance, other contact from staff and engagement in meaningful activity. In the PCAS group, 53% of residents were judged to be receiving good active support (ASM score >30), compared with 29% in the comparison group. There were no differences in participation in daily living or choice-making.

Engagement in meaningful activities

There was a modest difference between PCAS and comparison groups in engagement in meaningful activity.

Higher engagement was predicted by younger, more able white British residents, with less stereotypy but with more inappropriate speech; by staff who had worked in hospital and who were more knowledgeable about challenging behaviour and where staff provided active support.

The comparison group were more likely to think that challenging behaviour was learned negative behaviour, showed more teamwork and were more satisfied.

The PCAS group had more staff with a professional qualification, were more likely to think that challenging behaviour was caused by lack of stimulation, had attitudes more in line with a policy of community care, rated most care tasks as less difficult, and were more organised to deliver active support.

The results do suggest that some variables which have not until now been studied in relation to active support are associated with it. Professional qualification, knowledge and experience appear to be important as do some staff attitudes, clear management guidance, more frequent supervision and support and training for staff to help residents engage in meaningful activity.

Considerations

There are some major concerns with this study. First, it is not clear what approach the control group may have had in place that was not person centred support in some way. Second, it is not clear whether the effect is due to the training alone, as the 2 groups were combined for the variance analysis.

Some factors seemed to be important for positive outcomes that may be unrelated to the delivery of the training. For example, higher engagement was predicted by younger, more able white British residents, with less stereotypy but with more inappropriate speech; by staff who had worked in hospital and who were more knowledgeable about challenging behaviour; and where staff provided active support, this makes it difficult to know whether PCAS is ‘better’ than usual care, or if usual care already include some elements of PCAS.

There are also some limitations with the study. The non-random comparison group design does not allow us to be confidence that the changes were caused by the intervention put in place. The differences between the groups may reflect differences that were there before. Having said that, the analysis the researchers did may have suggested important factors to consider for successful implementation of personalised active support.

It is not possible to conclude that engagement in meaningful activity and relationships increased in the experimental group only that it differed from the comparison group. The identification of particular scale items in the regression analysis reflects their power as predictors rather than their validity.

Despite the limitations of regression as a method, it does seem that the way in which some of these issues matter is rather specific and that general ratings of, for example, management may be less useful than finding what precisely works to increase active support and, through it, resident engagement in meaningful activity.

McGill P, Cooper V, Honeyman G (2010) Developing better commissioning for individuals with behaviour that challenges services: a scoping exercise

Review question(s): 3.3

Organisations the authors were involved with:

1. Tizard Centre at the University of Kent

2. Challenging Behaviour Foundation

Type of study: Qualitative

Country: England, UK

Population: People with learning disabilities and behaviour that challenges – the people that took part in the research were families and carers and commissioners of care for this population

Quality score: +

Type of service: Community support, positive behavioural support and crisis prevention and management

Study aim

This study sought the views of families of individuals with behaviour that challenges and commissioners of services to find out more about the current provision of services and to look at what helps and what gets in the way of the process of local service development.

Findings

Qualitative themes

Access to support

‘The experiences of families demonstrate double standards when it comes to appropriate training – those who are trained and paid to provide support can exclude an individual and the responsibility for that individual rests solely with the family, who are untrained and un-supported.’ (McGill et al 2010, p13)

Choice and control

Families consistently identified a lack of capable local services. For some families this has led to an out of area placement for their son/daughter. This placement has occurred not as a positive choice but because it was the only option in the face of inadequate local services.

Impact on carers

The negative experiences of trying to access support service over time takes its toll on the health and wellbeing of carers. Bad experiences of services lowers families’ expectations of those services in the future.

Navigating care services

Carers said the time of transition between services is particularly difficult with families and carers having no idea where to go for information.

Respite care

Families often know what kind of service would be most helpful, but this is not offered to them or its not available in their area.

Transition

Commissioners were aware that children placed in residential schools were often placed out-of-area in the future, but they said there was a lack of joint working with children’s services to prevent this happening.

Working together

Families often said that they were not concluded and considered equal partners in planning support and services.

Barriers

Capacity

A minority of the commissioners thought that there was a lack of emergency support that might help to prevent out of area placements.

Most commissioners said it was difficult to find local providers for people whose behaviour was challenging and this might mean that people get placed out of area instead.

Knowledge and skills

Families often said that there was a lack of skill and expertise in behaviour that challenges.

Misconceptions

Commissioners found it difficult to assess the quality of specialist services being offered, it seemed too good to be true sometimes as they promised so much on their websites. They said that standard judgements (such as CQC ratings) were not enough for such specialist services and that a much more detailed focus on, for example, the quality of staff support was required. Sometimes families would think that the out of area placement would be better as they claim to offer more than what is available locally.

NHS–local authority interface

Commissioners reported a number of problems associated with continuing care. For many people who were placed out-of-area there was little resource to support bringing them back to the local area. It was difficult to get the care manager from the local authority involved and commissioners said the continuing care assessment arrangements had long waiting lists. This made it difficult to know exactly how many people needed specialist services in the area.

There were problems between the local authority and the PCT regarding commissioning. There were few instances of pooled budgets ‘no appetite for joint commissioning’.

Resources

A minority of the commissioners thought that there was funding/finance issues such as the difficulty of securing money to ‘double fund’ the transition between an out-of-area and in-area placement.

Roles and responsibilities

A minority of the commissioners thought that there was difficulties around the provision of services for people with mild/borderline learning disability. Some commissioners said that it was possible for preventative, early intervention at a younger age to reduce the likelihood of residential school placement but that there were limited incentives for children’s services to carry out such work as the costs during childhood were shared across agencies and savings won’t play out until they are using adult services. This suggested that they should think about a ‘whole of life’ perspective: Not seeing people – just children or adults who use children or adult services.

Facilitators identified

Commissioning

Most commissioners thought a national programme board to drive the development of local services would be a good idea but there was also a general view that any such initiative should be ‘mainstreamed’ as much as possible within existing performance management arrangements.

Staff skills

Most commissioners said it was a good idea to have more training and support for provider organisations, maybe even a nationally recognised module for care staff.

Implementation issues

Because of difficulties finding local providers, commissioner often fall back on using established out of area placements, even though this makes it difficult to monitor quality of care. Once and individual is placed there, service users and their families can resist being moved again into a local area.

Barriers to local service development

Lack of coordination between adult and child services; lack of a systematic commissioning framework based on good quality information about the quantity and nature of local need; lack of confidence in the ability of locally available providers to deliver high quality supports to people labelled as challenging; wide variation in the application of NHS continuing care criteria and associated inter-agency perverse incentives. With exceptions, continuing difficulties between local authorities and the NHS in coordinated and integrated working and lack of specification of the commissioner role so that wide variation in the nature and quality of commissioning practice. Family preferences (sometimes) for specialist, out-of-area placements perhaps in the context of earlier, local placement failures and lack of collaboration and understanding (in some areas) between commissioners and clinical support services. Commissioners considered and commented on a range of possible supports for their local practice.

Considerations

The main limitation with the study is that it only a ‘scoping’ study, intended to map out the issues ‘from a distance’ without, necessarily, being able to detect the detailed nature and generality of each issue. Only a small number of commissioners were interviewed and they all came from London or the South East, plus there was no information provided about how they were recruited, so we cannot tell if there might have been any bias in the selection process. In addition, only a small number of families (n=6) were interviewed, and there is very little information about the families to know if their views are likely to be representative of all service users. However, the Challenging Behaviour Foundation says ‘these experiences are not unique to the 6 families interviewed and are consistently raised by family carers who contact the Challenging Behaviour Foundation, often in crisis, for information and support’.

McGill P, Tennyson A, Cooper V (2006) Parents whose children with learning disabilities and challenging behaviour attend 52-week residential schools: their perceptions of services received and expectations of the future

Review question(s): 3.3

Organisations the authors were involved with:

1. Tizard Centre, University of Canterbury, Kent

2. A parent of a young man with severe learning disabilities and challenging behaviour and the founder of the Challenging Behaviour Foundation, and a postgraduate of the Tizard centre

Type of study: Survey

Country: UK

Population: Children

Quality score ++

Study aim

This study was about views of parents of children with severe learning disabilities and challenging behaviour who attended 52-week residential schools. They were asked about the support they got before their child went to residential school, whether the residential school placement support was a good quality, and right for what their child needed and things they wanted to happen and not to happen in the future, for their child.

Findings

Family experiences of support before their children went to their current residential school were nearly all negative. They said that professionals often did not give good advice. For example, they did not know about specific disabilities. Sometimes there was no advice available to them. Getting help with their children’s behaviour that challenges was said to be particularly problematic.

Parents were mostly positive about their children’s residential school placement. Having said that, they had some worries about the quality of care, how quickly staff changed and how much training junior staff had. The main thing they were unhappy about was how far the residential school was from their home. This was because it meant they could not see their children as much as they would want. They said they could not get much help to see them more, from education or council services.

Parents were very worried about their children’s future. They said that services were not good at making plans for their children’s future. Because of this, they expected that when their children leave their current schools there will have the same trouble finding them a new place to support them that they did finding their current placement. Some worried this may mean they would have to look after their child at home. They worried they may not be able to do this. Most thought the problem would be more to do with difficulty finding another place their child could continue to get an education, close to home.

The study says that family support is generally poor. The study findings suggest that offering more support for people to manage children’s behaviour that challenges – at home and in school – may mean children do not need to go into residential schools. Putting children in residential schools far away for the whole year can be bad in a number of ways. In particular, it can affect parents’ relationships with their children and can put vulnerable children more at risk of harm.

Considerations

The study is good because the researchers thought carefully about how to do it. They wanted to make sure people could be confident in their findings. They involved families early on. They used sound methods to collect the data and work out what it told them. They involved a good number of people and organisations.

It is limited in 2 main ways. First, it only reports parents' views and not children's views. We also do not whether parents' positive reports about schools are a direct result of the schools themselves; it could be that parents feel better about their family situation when their children go into residential schools. Other researchers have highlighted this (Abbott et al. 2001; Morris 1997). This is why it is important to note that children's views on residential school placements are not included in the study.

Secondly, while it is good that quite a large number of people have taken part in the survey part of this study, the people who took part were those that put themselves forward to do it – they were 'self-selecting'. The findings may not represent what you would find if you asked a wider range of parents. Also, a smaller number of people were involved in the telephone interviews.

McGill P, Vanono L, Clover W et al. (unpublished) Preventing the challenging behaviour of adults with complex needs in supported accommodation

Review question(s): 3.1

Organisations the authors were involved with:

1. Tizard Centre, University of Kent, Canterbury, UK

2. University of Kent from Dimensions (UK) Ltd

3. Challenging Behaviour Foundation, Chatham, UK

4. Dimensions (UK) Ltd

5. University of Kent from Kent and Medway NHS and Social Care Partnership Trust

Type of study: Randomised controlled trial

Country: England, UK

Population: Professionals/practitioners working with adults with learning disabilities and behaviour that challenges – there were 38 people in the new type of care and 43 in the usual type of care

Quality score: ++

Type of service: Supported accommodation

Study aim

To see whether a new approach that improves the quality of social care in supported accommodation was better than the usual way in reducing or preventing behaviour that challenges. People were then followed-up 12–18 months after trying the new approach or the old, to see if there were any differences.

Components/content

Service planning

Regular review

There were monthly meetings with manager to review progress against the standards set. Researchers encouraged the achievement of the standards using a variety of means.

Protocols

Developing and supporting the development of documentation

Links to other services

They used existing, local professional resources from outside dimensions. Staff were encouraged to seek advice and support from local community learning disability teams and other sources of potential support.

Specialist staff

Staff skills

The new approach involved coaching and training for the staff and manager. Managers were encouraged to draw in support from other parts of the organisation. This included a coaching resource which enabled managers to receive support with difficult supervision or management issues and a training resource which provided training for staff specifically related to active support.

Findings

Outcomes

Social care outcomes

Social care outcomes were measured by the setting and achieving social care standards.

The new type of care achieved the following:

activities and skill development, 84.0%,

communication and social interaction, 56.4%,

health, 77.3%,

physical environment, 73.8%,

relationships with family and others, 77.2%,

service staff, 75.7%,

service management, 80.3%,

wider organisation, 68.0%,

overall 75.2%.

Clinical outcomes

The main outcomes that the study measured were changes in the Aberrant Behavior Checklist (ABC) score between the groups before and after the new approach.

Behaviour that challenges

The reduction in ABC total scores in the new care approach group was significantly greater than in the usual care group.

Satisfaction

Job satisfaction

Staff in the new care approach homes showed higher satisfaction at the second time it was measured while staff in the usual care homes showed lower satisfaction. The difference in stress scores between staff in the new care approach and control groups was not significant at the first time it was measured, but it was at the second time.

Service use

All staff contact measure was not significantly different between the 2 groups.

Things that helped

It helps to change thinking about behaviour that changes as being a problem of the person but instead a problem that may be located in the system and environment. Authors say that relatively simple changes and better use of existing resources can make positive changes to the quality of social care people receive and this then impacts on behaviour that challenges.

Things that got in the way

High turnover of staff in the social care sector is often a problem. This can make it difficult to get the same members of staff to complete questionnaires over time. Sometimes it is not possible to detect an effect, not because the approach isn't a good thing, but because the people in the usual care are trying hard to make improvements to the quality of their care too.

Considerations

This study hasn't been published yet. This means it hasn't been made available publically or been sent to peer review (where other academics and topic experts look carefully at the study and make suggestions to improve it or point out any inaccuracies) and there is a little bit that is incomplete on inter-rater reliability which tells us how reliable the tools used to measure outcomes were.

Otherwise this is a very good study for answering questions about effectiveness because any differences between the 2 groups are as likely to be in 1 group as another. The authors made sure that other sources of bias, were minimised using established techniques. This made sure that other important differences were ‘smoothed’ out and the 2 groups were as similar as possible, so that the only explanation for the differences should be the difference in care that they experienced.

Because of funding and other restraints, authors were unable to follow-up over a longer period of time to see if any of the positive changes continued over time.

McKenzie K, Paterson M. (2010) Evaluating an assertive outreach team for supporting clients who present behaviour that challenges

Review question(s): 3.1, 5.1, 5.2

Organisations the authors were involved with:

1. Consultant clinical psychologist, University of Edinburgh School of Health, in Social Science, Medical School, Edinburgh

2. Learning Disability Service, West Grove Annexe, Waverley Road, Melrose

Study type: Process evaluation. Authors ask staff who have worked in the new assertive outreach team what they thought about it, what worked well and what could be improved. They also looked at the reduction in challenging behaviour, but this was not compared to another group so we don’t know if this means the service is better than what is done usually in any area, or that it is better only for that service in that area

Country: Scotland.

Population: Staff from an assertive outreach team and service managers, and staff from a community learning disability team who worked with people with learning disabilities and behaviour that challenges

Quality score: -

Type of service: Assertive outreach team (AOT)

Study aim

This study evaluates an assertive outreach team. The team aim to help support people with a learning disability with behaviour that challenges in their own environment. The main aims of the service are to:

- prevent out-of-area placements

- prevent delayed discharge if people are admitted to hospital.

Findings

Key features of the service

The AOT assessed and supported individuals who were in danger of their community placement breaking down because of severely challenging behaviour. This involved:

conducting assessment reports and intervention plans,

crisis prevention and management,

supporting people in a person-centred way,

addressing staff skills.

Summary

Why it worked

Multidisciplinary collaboration

Preventive, not reactive approach

Practitioners who referred people into the service said it led to a reduction in challenging behaviour in most (71%) of those people. The results indicated that the AOT provided a locally based service that generally worked well and properly, and that was fair and easy for people to get to use. The main strengths of the team were said to be the staff's skills and professionalism. The weaknesses reported most often were about liaison, communication and being clear about the role and remit of the team.

What also helped

Collaborative teamworking

Examples of what helped included: people having the time and skills needed to work in partnership with carers and other professionals.

Staff skills

Staff were said to have the skills and knowledge they needed to do their work. They were said to be able to stay objective in difficult situations. They were also said to be enthusiastic about working with other people.

What got in the way

Knowledge and skills

Where staff have only limited knowledge and skill of staff, this can get in the way of delivering an effective service.

Organisational structures/cultures

Some communication was not good. Some people said the service did not provide enough feedback.

Response time

It could take a while to accept cases and this was reported to be problematic. It could take a while to respond in crisis.

Relationship with wider LD service and team

'Still very separate from LDS.'

Roles and responsibilities

There is a reported need for the service to be clearer about who does what and how it works with others.

Ways of working

There is a need for staff in the service to work in a methodical, evidence-based way. This means everyone gathers the same type of information in an agreed way and that the information is used to help make decisions.

Considerations

The study is partially relevant to us. It was only looking at what happened after the assertive outreach team was put in place. It looked at the effect the service had on behaviour that challenges, that is to say, it didn't look at other effects of the service. The management, treatment and prevention of behaviour that challenges alone is under the remit of the clinical guideline. Information about how the service might prevent delayed discharges and breakdown of community based placements is relevant to our guideline but the study design does not allow us to confidently say whether the service made a difference to these areas.

The survey included useful information on what worked well and what didn't work so well. However, the authors say that, 'The evaluation would have been greatly improved by service user involvement, and this is an area that needs to be addressed in future evaluations' (p38).

National Development Team for Inclusion (2015) Informing the service model: a report about the experiences of people with learning disabilities and families

Review question(s): 3.3

Type of study: Qualitative study.

Country: UK

Population: Respondents – families/carers and adult service users; service users: people with learning disabilities and behaviour that challenges

Quality score: +

Study aim

The study wanted to know about what people who use inpatient services and their families think about services. The findings from this study were to be used to inform the development of a new service model for commissioners.

Findings

Access to support

People did not get the right help at the right time and this meant things could get worse. Things getting worse could involve the person needing help going into an inpatient unit. Many families had been through this experience. Often it meant that the person needing help had to go far away. Families had found it difficult to get support from CAMHS, speech and language services and occupational therapy. They also found it hard to get help from social workers and psychologists. Often the waiting lists are over a year.

Choice and control

Families often do not have choice about what services they can get to use through social services. They think personal budgets and personal health budgets should be much easier for families to be able to use. Also, people with complex needs are often not able to have the person-centred care they need to stay safe and well in their local area.

Family life

People should go into hospital close to home. Families said that placements were often far away. This made it hard to visit and keep in touch. It also meant the people in the placement were not able to spend time in their local community. People thought it should be possible for people living far away to have access to Skype so they can talk to their families privately.

Human rights

People were very worried about how the Mental Health Act sections are used. One family said that it meant people were not able to stay in their local community even though national policy says staying near your home is a good thing. People thought that it was too easy to renew a section 3 and that parents' views were missed out from this decision sometimes. Overall, people were worried that people's human rights were not being respected.

Health and wellbeing

Nearly all families said their relative's health was bad while they were an inpatient. Staying in hospital could make them more ill, or ill in different ways.

Information

People talked about not being given information on what services are available or how to get them.

Staff skills

People said that staff did not have the right skills to support people in inpatient units. They also talked about something called 'diagnostic overshadowing'. Here, this means that professionals assume the way a person behaves is because of their learning disability when actually it because of a mental health problem.

Linking hospital and community

There were mixed reviews here. Some people said their hospital staff had good links with services in the community. They said this could be very helpful. Others did not. This could mean that people find it difficult to get back to living their lives outside hospital after having been an inpatient. Related to this, people said that often services are not good at planning how people will move from hospital to the community.

Types of services

There needs to be local, small and specialist inpatient provision for people who might need it. Too many people are getting sent far away and this makes them and their families unhappy. Hospital services should be part of a pathway that also includes community services. The pathway should also work to help people stay well and not get worse.

Services working together

Families said that services did not work well together. Sometimes it can be difficult to get social services to get involved in discussions. Sometimes health and social care services argue about what is best for a person, and who should pay for their help.

Advocacy

Having someone to speak on your behalf, or help you with things, can be useful. In hospital though, people using services can sometimes see advocates as just another member of staff in charge.

Commissioning services

Commissioning services means planning, organising and paying for them, and reviewing what they are doing. People said it is best when organisations work together to do this. This is particularly important as people move from children's to adults' services. It is important that services help people throughout this process. They should not just stop because someone reaches a certain age.

Family involvement

Services need to work together with families on a day-to-day basis. Sometimes services do not recognise the important role families can play in helping their family member stay well and happy. Families should have more power and need to be involved on a day-to-day basis. There should be written agreements with families about how long their relative should be in hospital. These should be updated if things change.

Considerations

This study was relevant to us. It looked specifically at things that help us answer the questions we have asked. It also involved a reasonable number of people. It was limited because the way it is written means we cannot be clear how many people said the same thing. The methods were not clearly described and we do not know how the researchers organised the information they gathered. Also, it is not always clear which conclusions come from the people in the study and which come from the authors.

The following evidence statements are from qualitative views and experiences studies and qualitative process evaluations of the views of researchers and practitioners.

Perry J, Felce D, Allen D, Meek A (2011) Resettlement outcomes for people with severe challenging behaviour moving from institutional to community living

Review question(s): 3.1

Organisations the authors were involved with:

1. Welsh Centre for Learning Disabilities, Centre for Health Sciences Research, School of Medicine, Cardiff University, Cardiff

2. Wales, UK – Abertawe Bro Morgannwg University NHS Trust Learning Disabilities Directorate, Wales, UK

Type of study: Quasi-experimental

Country: Wales

Population: Adults with severe challenging behaviour who needed ongoing health care – ages ranged from 36 to 67 years, and the average age was 47, there were 13 males and 6 females

Quality score: +

Type of service: Moving into community living

Study aim

This was a study of people who had been moved from a learning disability hospital into new, purpose-built bungalows. The authors looked at the difference this made to people's quality of life and lifestyle. They had aimed to create 2 groups that moved at the same time., but this wasn’t possible because of delays in the new accommodation becoming available.

Timing of data collection

There were 2 groups of people in this study. The ‘stayers’ were the people who stayed in the hospital. There were 17 of them. The ‘movers’ were the people who moved into the bungalows. There were 14 of them in this group – 12 who moved into the bungalows at the same time and 2 who moved earlier.

There were 4 time points at which things were measured in this study, as follows:

- time 1 – before anyone had moved,
- time 2 – when a few had moved into the bungalows and most people were still in hospital,
- time 3 – when the majority of people had moved into the homes and a minority were still in hospital,
- time 4 – when everyone had moved out of hospital.

The researchers compared the measurements in 4 different ways, as follows:

- comparison of ‘stayers’ measurements at time 1 and time 2,
- comparison of ‘movers’ measurements at time 2 and time 3,
- comparison of ‘movers’ measurements at time 3 and time 4,
- comparison of everyone’s measurements at time 1 and time 4: this is the overall picture of what things are like ‘before and after’.

Findings

Social interaction or support

Social contact: There was no significant difference between the ‘stayers’ and ‘movers’ for frequency of family contact at the first time measured, but there was a difference at the second time point this was measured. The ‘stayers’ had a bigger increase in the frequency of social activities after they moved compared to before they moved.

Behaviour that challenges

There was significant difference between all groups before and after moving measured by the ABC scale.

Engagement in meaningful activities

There was more engagement in constructive activity for the ‘movers’ before and after. There was an increase in comparison of domestic activity for all of groups before and after moving.

Physical environment

The community settings were said to be more homelike and this was statistically significantly different for the movers at time 1 and time 4.

Considerations

There may not have been many big differences, but this also means that things didn’t get any worse. So there’s no reason to believe that living in the community is any more ‘risky’ when people are moving out of hospital after a long time.

Authors say that the differences they found might not just be because of the change of setting. It could be just as likely that it was because the staff in the old hospital had training in new working methods before people moved to their new homes. This included, for example, putting in place positive behavioural supports.

The design of the study was limited for a number of reasons. It wasn’t possible for researchers to stick to the plan of creating 2 groups (the earlier movers group and the later movers group) to compare because of delays in the accommodation being available. So the 2 people who moved out early were combined with the ‘movers’ group, even though they moved out into the bungalows at different times, which isn’t ideal.

It was a small sample so sometimes statistical tests can’t detect a difference between the groups. The researchers looked at lots of different measures which, because there weren’t a lot of people involved, means they were more likely to make a mistake by saying that there was a difference where there wasn’t.

It would be good to follow up to see if the new working practices stay in place over a longer period of time than was allowed for in the time of the study.

Phillips N, Rose J (2010) Predicting placement breakdown: Individual and environmental factors associated with the success or failure of community residential placements for adults with intellectual disabilities

Review question(s): 3.1

Organisations the authors were involved with:

1. Worcestershire PCT, Worcester, UK

2. School of Psychology, University of Birmingham, Edgbaston, Birmingham, UK

Type of study: Observational, correlational.

Country: England, UK.

Population: Residential care staff for adults average age 43 years – 20 people were in the group where the placement had broken down and 23 were people were in the group where the placement had been maintained

Quality score: -

Type of service: community residential placements

Study aim

The study looked to see what organisational factors – including staff beliefs about an individual's control of behaviour that challenges – are associated with placement breakdown.

Findings

Adaptive behaviour

People were more likely to be in the placement breakdown group if they were significantly more able overall. They were also more likely to be in this group if they were able to be self-sufficient as measured by a specific scale used in the study (the ‘ABS-RC2’).

Behaviour that challenges

The breakdown group were more likely to be more challenging in terms of how often and severe the following behaviours were:

antisocial behaviour,

‘temper tantrums’/verbal abuse.

The breakdown group were also more severe in terms of what the study calls ‘sexual delinquency’.

Mental health

Individuals experiencing placement breakdown were significantly more likely to have had a psychiatric diagnosis than those in the placement maintained group.

Risk of hospital admission

People in the placement breakdown group were more likely to have had 1 or more acute admissions to an acute psychiatric or behaviour service.

Organisation and staffing

Only senior staff in the placement breakdown group thought people were in control of their behaviour that challenges. Other members of staff were no more likely to believe this. Authors suggest that placements are more likely to break down if staff believe that the person can control their behaviour that challenges is in the person’s control and those staff have authority to take action.

Services in the placement breakdown group were rated as not working as well as those in the placement maintained group. This was shown in terms of staff resources – energy levels of staff to implement interventions, physical environment (personal space, light, ventilation etc.) – the social environment (amount of staff contact, assistance, interaction styles etc.) and the effectiveness of the administrative systems

Considerations

This is not a study design that can tell us whether 1 way of providing a service is more effective than other in terms of placement breakdown.

Study limitations

There may be some things which make a difference to whether or not a placement breaks down that have not been included in this study. From a small sample size it is difficult to know whether all factors have been identified, or that the staff and people using the services included are similar to others.

However, the findings are supported by findings in other studies that staff and other organisational factors can affect how successful a placement will be.

Reid C, Sholl C, Gore N (2013) Seeking to prevent residential care for young people with intellectual disabilities and challenging behaviour: examples and early outcomes from the Ealing ITSBS

Review question(s): 3.1

Which organisations were the authors involved with:

1. Intensive Therapeutic and Short Break Service (ITSBS) Ealing Service for Children with Additional Needs, London

2. CAMHS-LD, Ealing Service for Children with Additional Needs, London, UK

3. Tizard Centre, University of Kent, Canterbury, UK

Type of study: Single group, before and after

Country: England, UK

Population: Young people aged 7–17 at risk of residential care placement

Quality score: -

Type of service: Intensive support and short breaks

Study aim

The aim of the study is to present early outcomes and case examples from the Ealing Intensive Therapeutic and Short Break Service.

What the service involves

- Assessment
- Functional behavioural assessment (FBA)
- Specialist staff
- Agency carers
- Agency carers trained to work in the home and community with the young person and their family.
- An increase of existing direct payment carers
- Clinical/ educational/behavioural psychologists
- Family link foster carers
- People who take the young person into their own home for overnight stays and support
- Sitters who come to the family home
- Training
- Whole network training is delivered to support implementation of interventions to staff and families

Types of support

- Positive behavioural support
- An individualised PBS Plan developed in collaboration with the young person's family and network
- Supporting the family

Findings

The authors found that, after using the service there was a significant difference in behaviour that challenges as measured on the Developmental Behaviour Checklist. They found an effect size of 0.44 which is a moderate to large effect. They also found a significant reduction in the concerns of parents after using the service with a large effect size of 0.6.

Study limitations

This is a small pilot study so, looking at this study alone, we cannot draw very definite conclusions. There were some difficulties in measurement. In particular, people used the service for varying lengths of time so the ‘before’ and ‘after’ measurement points were not the same for everyone.

Only the data routinely collected at the service were used for this study. The study didn’t compare the group of people using this service and families with people using the normal kind of service.

There was also no follow-up information provided. This means we don’t know whether the benefits of the service lasted over time. This would be particularly important for the younger children who were moving into adolescence because the authors say the risk of residential placement was related to age.

Robert M, Leblanc L and Boyer T (2015) When satisfaction is not directly related to the support services received: understanding parents' varied experiences with specialised services for children with developmental disabilities

Review question(s): 3.3

Organisations the authors were involved with:

1. Psychoeducation et Pyschologie, Université du Quebec, Canada

Type of study: Qualitative

Country: Canada

Population: Parents of children with developmental disabilities

Quality score: -

Study aim

This study aimed to find out what parents thought about specialised support services. It wanted to know what they thought worked well and less well and why.

Findings

Positive experiences

A large number of parents were satisfied with their experiences of specialised services. Parents were most positive about the practical support offered by professionals. When professionals had skills to do this, it was helpful.

The services they most valued were those that help them to understand their child better, to communicate with their child better and to manage difficult behaviours. They also thought the professionals were committed, dedicated and compassionate and they thought those things were good.

Negative experiences

There are 5 themes related to parents' negative experiences. These concerned the following.

- a change of support worker – this was difficult because it takes time to build trust and a relationship,
- the length of time it took before being able to access services – this was sometimes too long,
- the services offered not being right for the child's needs or the family situation,
- access to certain services being based only on diagnostic criteria,
- services not recognising parents' contribution and expertise as part of the way they work to help the child. – parents know a lot about their children and so thought they can really help services support the child in the right way.

Satisfaction/dissatisfaction

The study found that there are a number of things which affect how happy or not parents feel with a service. One of these is whether parents consider themselves to be experts or non-experts. The other is what parents think about what the service is trying to achieve. This means that parents who are happy with services tend to see support workers as experts on their child's situation and the goal being to improve daily life with their child.

Parents who are not happy with services tend to think they are experts on their child. They want a bigger decision making role in how the service and support is planned.

Considerations

This is a lower quality study overall because the sample size is small and involves people from 1 place only. It may not represent a large or diverse group of parents. Also, participants had to volunteer to take part. This means that the sample could be biased – the views of the people who took part may not be representative of those of others who did not take part. On the other hand, the way the information was collected and analysed is good.

Another thing to bear in mind is that the children of participants in the study are described as being diagnosed with autism spectrum disorder or intellectual disabilities. The paper does not mention behaviour that challenges in terms of the children in question, so may not be relevant to us. Having said that, the researchers did ask a question on how parents managed behaviour that challenges.

The was conducted in a city in Quebec, Canada, which has some similarities to the UK, but which is not exactly the same.

Shared Lives Plus and KeyRing (2012) Closing the Winterbournes. Liverpool: Shared Lives Plus

Review question(s): 3.2

Which organisations authors were involved with:

1. Shared Lives sector

2. KeyRing Living Support Networks

Type of study: Process evaluation. The authors from these 2 organisations tell us about their experience of what helps and what gets in the way of people being able to move into family homes in their community.

Country: England, UK

Population: Adults (16 and over) who are described as “challenging” or who have complex needs

Quality score: -

Type of service: Moving into family and community living

Aim of study: In this report the authors described what they found were successful approaches to help people move out of assessment and referral units in the UK and move into - or become regular visitors to -family homes.

Findings

The authors said that a number of things were needed for the scheme to work:

- Sharing information
- A locally based community volunteer
- Training
- Day services
- A tenancy agreement, so if the person doesn't need the support anymore, they don't lose their home.

Things that got in the way of moving into the community

In their experience, the authors believe that, currently, being supported in treatment and referral centres can stop people moving back into the community. This is because:

- people's behaviour tends to be assessed in an unnatural, medical environment which might affect how they feel and this might also be shown in their behaviour
- the centres focus on a person's physical and mental health. It does not focus on things like promoting living an ordinary life, choice and independence
- some staff are overly cautious about taking risks.

Things that helped moving into the community

The authors make some suggestions about what might work better in helping people move into the community.

Brokerage and advocacy

Having an advocate can help people with learning disabilities and their families to know what their options are, including using personal budgets. They say more care providers should employ people with learning disabilities as advocates.

When a person is in a setting like an assessment and referral centre and they are not free to come and go as they like, this should be regularly reviewed. The person should have an advocate looking out for them.

Commissioning

It would help if professionals think more about different ways of doing things. They should look for the option that offers the person the most independence.

It would help if payment for services was based on what services actually achieved, so that different service providers became available. The costs might be higher in the short term, but then savings are made in the long term as people move into community living.

Things to think about

The study was only partially relevant to us as it isn’t always clear if the people the report is talking about people have learning disabilities and behaviour that challenges. People in our population have a wide range of needs and it wasn’t clear if this scheme is suitable for everyone.

The design of the study was limited for a number of reasons:

We don’t know very much about how the information was collected. We don’t know whether all the information that was collected was reported or only some of it.

A lot of the time the report makes suggestions for the future, but it is not clear whether these have been tested and found to work in practice. Because it is written by the organisation themselves, and not by an external evaluator, the aim of the report may be to promote the organisation and not see if the scheme works or not. The authors point out that their organisations are not particularly well known and people don’t know that this kind of arrangement is available to them.

Stenfert Kroese BS, Rose JL (2011) Mental health services for adults with learning disabilities

Review question(s): 3.3, 5.1, 5.2, 5.3

Organisations the authors were involved with: The Judith Trust

Type of study: Qualitative

Country: UK

Population: Participants: adult service users and practitioners

Type of service: Adults with learning disabilities and mental health problems

Quality score: +

Study aim

The study aimed to find out what people using services and professionals think are the personal qualities needed by people working in this field. The study also wanted to find out what people thought worked well and less well in terms of services for adults with learning disabilities and mental health problems, and what could be better.

Findings

What works well

There was strong agreement that services are good when they are in the right place at the right time. They are good when they listen to what people want and respect them as people. Services are also good when they can find and keep good staff.

To make services work well staff need to have the right skills and knowledge. They thought that services could make sure this happens by:

- being clear in job descriptions and person specifications about what personal qualities staff need,
- making sure that when staff start they have proper training – they should also be able to watch others doing the same job, to see how things get done,

- having specialist expertise – people said that the areas of specialist expertise most useful are diagnosis, medication, counselling, psychology and relaxation,
- good supervision by qualified managers,
- having ongoing training which should also be given to staff in residential settings,
- being interested in the people they help,
- being treated well themselves, and to not having huge amounts of paperwork or workloads that are too big for them to manage,
- being able to communicate easily with different services,
- being clear about what they are trying to achieve when they work with other services.

In terms of how services should work with families, they need to:

- think about how to support carers and families,
- help people as early as possible, so that their problems don't get worse,
- think about the reasons why people have mental health problems,
- take into account the person in the context of their family if they are in close contact with their family,
- have regular meetings with people using services and reviews of the help they are getting,
- have 1 professional in place who can help coordinate services and be a single point of contact for the person and their family.

Considerations

This study is relevant to us because it is about the views and experiences of people using and working in services. It has been carried out well and it involves a range of people. There are some concerns about how relevant the views in the study are to our population and setting. It is not specifically about the population of people with learning disabilities and behaviours that challenge. However, these are services that we are interested in for our work, and some people with learning disabilities and behaviour that challenges may well use them. Also since the study, only includes the views from service users in 2 locations, they can't provide a reliable picture of what people think across the UK. You will need to think about what things are like in other areas.

Toogood S, Saville M, McLennan K, McWade P, Morgan G, Welch C, Nicholson M (2015) Providing positive behavioural support services: specialist challenging behaviour support teams

Review question(s): 3.1, 5.2, 5.3

Organisations the authors were involved with:

1. Behavioural Solutions and Bangor University

2. Halton Borough Council

Type of study: This is a process evaluation that looks at the development of a service

Country: England, UK

Population: Adults and children with intellectual disabilities who live in 1 of the 3 commissioning local authority areas, and present a significant risk of engaging in challenging behaviour

Quality score: -

Type of service: Mobile positive behaviour support teams

Study aim

This study looks at the development of the positive behaviour support teams, their design, structure and sphere of operations.

Findings

Authors state that the service works to address behaviour in early intervention, crisis prevention, technical assistance and placement development.

Key features of this service

Assessment reports and intervention plans – these are completed so that stakeholders have all the information they need about behaviour and its function. Plans cover ways to enhance and enrich quality of life and lower the occurrence and impact of challenging behaviour, particularly through teaching and supporting alternate behaviour.

Care pathways – these are part of the service to help prevent delays in people getting the help they need, and to make sure they get the right kinds of support. PBSS is defined by clear pathways that are closely monitored.

Crisis prevention and management

Data based support – this service requires objective measurement of behaviour and events in order to understand what difference it has made. Function-based support – people are given support that is tailored to the level of function they have. This is also:

- the least restrictive support,
- minimally intrusive support,
- made up of a number of different types of support or service, as needed,
- support that happens at the same time but at different levels, for example, support for the person, support for the person's family, support in local communities etc.

Placement development – behaviour support staff work with stakeholders to create packages of support especially for that person. Personalised service design sometimes requires a new service to be developed. Other times existing services may be enhanced, modified or extended. A second way involves helping displaced persons to move back to their areas of origin, and into better quality and lower cost options. This should prevent placement breakdown.

Mobile behavioural advisors

Person-centred support – BSS staff work with professionals and staff in mainstream intellectual disability services to support individuals and their family members. PBSS staff contribute support that is person-centred.

Positive behavioural support

Staff skills – the principal manager is a board certified behaviour analyst 1 (BCBA). Care Managers are also BCBA or hold a masters degree in applied behaviour analysis and are in the process of completing fieldwork supervision required for certification. Assistant behaviour analysts hold a masters degree and are supervised by a BCBA. Behaviour support workers provide help with assessment, intervention and other tasks such as data recording and analysis (board certified behaviour analysts are practitioners certified by the Behavior Analysis Certification Board (BACB)).

Training – there should be training and mentoring for professionals from other agencies.

Summary

Why it should work

This service can increase parents’ confidence when responding to behaviour that challenges. It also provides the chance to intervene early. The aim of early intervention and prevention is to prevent problems happening by working with children and their families to:

- build new behaviour
- make new, more positive memories and associations, and
- help improve quality of life.
- There is flexibility regarding assessment and intervention.
- Partnership and collaboration – this intervention should begin with the person and should include others with whom he or she has a close and significant relationship. Professionals are partners in the service. They contribute by providing knowledge, insight, expertise and resources. This will vary between individuals and should work towards whatever a person needs to be successful.

What also helped

It is important for services to be designed well, as well as for them to address crisis response and management. Sometimes services need to be able to create tailored, personalised packages of care that are robust and affordable, and which will last.

What got in the way

The authors note it can be difficult to run the services on a bigger scale. They say that often services tended to copy the outward features rather than what the service model actually does. For example, services recruited community-based practitioners with a role to support people with behavioural challenges. Often though, it wasn't clear to them that this meant they should provide individually tailored, function-based, behavioural intervention.

It is also important to have a certain type of practitioner in this service – a board certified behaviour analyst. There aren’t many of these in the UK.

Considerations

This is a process evaluation that can tell us about how a service was developed and put in place but not whether it worked better than another at achieving what it set out to. It also doesn’t tell us whether the service worked over the long-term or whether someone else could do the same thing.

There may be many reasons why this service could be successful in 1 area, but not another. Not all of these reasons will be explored or explained by this study. Therefore, we should treat the results with caution on their own. We can look at them alongside findings from other studies of this type though.

Settings into the community: since 2013, only 20 people have moved into the community.

Economics

No economic modelling was conducted for this research question.

Expert testimony

The need for expert testimony

We had a lack of evidence about best practice in the implementation of a service model for people with learning disabilities and behaviour that challenges. We wanted to know what people who experienced accessing different servicers said worked and did not work.

Testimony

The full testimony from the expert witnesses can be found in Appendix E. A brief summary of their testimony is given below.

The expert witness in this case was a group of 4 people from Devon that could provide different perspectives on how to provide support around a young person in the community. This included hearing from a young woman receiving services, her mother, the service commissioner and the service provider providing services to the young woman.

The key point from the experts by experience was that the service needs to be built around the person. ‘You cannot squeeze a person into existing services that are often a very poor fit for a person’s needs’ (commissioner expert p1).

The experts also emphasised a number of things that are key for services and commissioners working with a person to get right. These include:

- sharing the decision-making with the individual, defining outcomes with them and making all care plans outcomes-focused
- matching the person and their key support workers with similar interests
- ensuring staff understand the complex behaviours of people and can anticipate idiosyncratic triggers, avoid distressing situations and have the energy and interests to engage people in the things they like to do
- having a working document that outlines what works for the person
- enabling a continuing of approach, so if a person is under mental health care or a particular package is working, don’t take things away when people leave the care of an intensive service.

When it comes to services working together the experts highlighted the need for systems working, especially with the police and CJS, housing, and primary and acute healthcare. It was also key that the commissioner develops a mature and trusting relationship with the provider which allows for flexibility so if the core team decides that they want to change the style and shape of direct support that is permissible and easy to do.

Planning and commissioning

The experts highlighted a number of things that can help ensure service planning and commissioning works well. These include:

- Know your population and have a clear process, for example maintain a dynamic register of adult services so you know who people are and the services they are using.
- EHC plans provide a way to ensure continuity of care when young people leave education.
- Separate accommodation and support. This way if a service provider ever struggles the person does not lose their home.
- Take a long-term view and be realistic about how long it can take to help people feel fully settled after years, sometimes decades in hospital. Savings will take time to show in the system.

- Use individual service funds that include a contingency amount of funding to be used for 'what if' scenarios, and up front recruitment training and induction of staff as well as providing the direct support to the individual.

Things that get in the way

The experts by experience view was that any form of group living is seldom the solution for people who challenge services. The service provider expert said 'for people that have their own troubles and need a particular environment then it is difficult to achieve this if there are several people living in the same environment' (p1).

Service model

The experts said that in their experience a model that delivers a bespoke service works best for people with learning disabilities and behaviour that challenges services. They suggested that commissioners should work with the person and their family to produce an Individual service design (ISD), then put that ISD into practice avoiding too much compromise because of what already exists. Other key components of the model would include:

- making effective use of a personal health budget (PHB) and individual service fund (ISF)
- ensuring that the person and their family make final recruitment decisions and each person has their own dedicated and matched staff team.

Inpatient services

The service provider expert highlighted 2 things that get in the way of inpatient services working well. First, the expert said it is difficult for any inpatient service to be effective in treatment plans unless these plans are for a short period of time and very treatment focused. Second, inpatients services ability to engage effectively with the person and work in partnership with the person's family and any community supports that person may have. When it comes to care and treatment reviews (CTR), the commissioner expert was of the view that while they are helpful they invariably rely on the psychiatrist at the hospital in approving discharge. Additionally, where individuals are under Home Office restrictions this can create added complexity in discharge planning as restrictions need to be factored into the individual service design and also the working policy.

Other relevant expert testimony

One of the expert witnesses that gave evidence on best practice for supporting children, young people and adults with learning disabilities in the community said that a 'bespoke' model worked best for delivering services to individuals in the community. See expert testimony in section 3.1 for further detail.

Evidence statements

For details of how the evidence is graded and on writing evidence statements, see Developing NICE guidelines: the manual.

SM1	**Understanding whether a care pathway approach is effective overall** A 'care pathway' describes the journey people should take through and between services. We did not have any studies that allowed us to say confidently that taking a care pathway approach is better than doing things a different way. This was because we did not have studies that compared the care pathway approach with doing things in a different way.
SM2	**Understanding what experts by experience think of the care pathway approach**

	We did not have any studies that describe what people think about a 'care pathway approach' particularly.
SM3	**Using a care pathway model – different people working together** Two moderate quality UK evaluations Ahmad et al. (2002 +) a process evaluation (n=unspecified) and Devapriam et al. (2014 +), a single-group, before and after evaluation (n=24) and 1 low quality UK process evaluation Buxton et al. (2004 −) (n=unspecified) found that working together is very important to making care pathways work well. These studies found that a wide range of people need to be involved in planning a new care pathway, putting it in place and making it work. These people should come from a range of organisations. They should have different skills and knowledge. All these people need to be clear about what it is that the whole group is trying to achieve. People involved need to think about what else is happening locally, regionally and nationally that could affect care. They need to make things join up. They could do this by having regular meetings where people look at how things are working.
SM4	**Using a care pathway model – having a single coordinator** Two moderate quality UK evaluations Ahmad et al. (2002 +), a process evaluation (n=unspecified) and Devapriam et al. (2014 −), a single-group, before and after evaluation (n=24), found that having 1 person coordinate a care pathway approach was helpful. These 2 evaluations both focused on assessment and treatment of people with learning disabilities. One of them, Ahmad et al. (2002 +) focused on a pathway for behaviour that challenges specifically. This person can help keep the work to put the pathway in place on track. They can also help to make sure that the person with learning disabilities moves from 1 service to another smoothly. In the other study, (Devapriam et al. 2014 −) this person was a band 6 nurse working full-time. We do not know from the evidence whether it was something about this particular person, or their skills that made the coordinator role work.
SM5	**Using a care pathway model – being clear about how long things should take** Two mixed quality UK evaluations, Buxton et al. (2004 −);, a process evaluation (n=unspecified) Devapriam et al. (2014 +), a single-group, before and after evaluation (n=24), found that it can be helpful to be very clear about how long different parts of treatment and assessment should take. These were both studies of assessment and treatment in specialist inpatient units for people with learning disabilities. Professionals in the Buxton et al. (2004 −) study decided that it should take 12 weeks for assessment and treatment. We do not know how they decided this from the study. The study by Devapriam et al. (2014 +) did not say how long it should take for people to be assessed and treated but they did say it was helpful to have clear stages and timescales. Neither study compared pathways of different lengths of time. We therefore cannot say, from these studies, exactly how much time it should take for someone to be assessed and treated in an inpatient unit.
SM6	**Lack of local services is a barrier to care**

	Two low quality UK studies of parents', families' and professionals' views Challenging Behaviour Foundation (2015 −);, a process evaluation (n= 5 services) and La Valle (2015 −), a qualitative study (n=61 parents/carers; n=128 practitioners) said that not having the right services available locally, at the right time, was a problem. One study, La Valle (2015 −) found that parents could not get support at home even when they had agreed with the council they could manage the money available to pay for their care ('personal budget'). This was because they wanted home-based services in particular but these were not available for them to buy. They wanted home-based services because they thought these were very important. They thought good home-based services helped make sure their children did not have to go into residential care.
SM7	**Professionals need to understand behaviour that challenges** Three low quality studies of parents', families' and professionals' views found that when staff did not have the right knowledge and skills, this was bad for service delivery. Two of these studies were from the UK Challenging Behaviour Foundation (2015 −), a process evaluation (n= 5 services) and La Valle (2015 −), a qualitative study (n=61 parents/carers; n=128 practitioners) and 1 was from Canada, Robert et al. (2015 −), a qualitative study (n=15). Some said that key workers in particular did not have the right experience. It was also particularly difficult when key workers left their jobs and they were not replaced by someone else quickly (La Valle 2015 −). In another study, people said that schools could have very little expertise in behaviour that challenges (Challenging Behaviour Foundation 2015 −). People said that staff in short breaks services, in particular, needed to have the right skills. They needed to be able to understand and respond to the family's needs. This was particularly about making an approach called 'positive behaviour support' work well (Challenging Behaviour Foundation 2015 −). Positive behaviour support is a way of helping families work with their children to develop new, helpful behaviours. The idea is that they can then use these instead of the behaviour that challenges. Parents in 1 study said that it was very helpful when staff knew how to tell them specific things they could do, or change, to help manage behaviour (Robert et al. 2015 −).
SM8	**The way services are organised and paid for** Two UK studies of what people think Challenging Behaviour Foundation (2015 −), a process evaluation (n= 5 services) and McGill et al. (2006 ++), a survey (n=87), said that the way services are organised and paid for can make it difficult to get what you need. One study found that health services often bought a big group of services or activities all together and payed up front. This way of doing things is called 'block contracts' or 'buying in bulk'. People said doing this could make it difficult for services to be made more personal to the individual later on. They said it could sometimes make it more difficult for professionals to work together too (Challenging Behaviour Foundation 2015 −). One study talked about who pays for what between the council and the education service (McGill et al. 2006 ++). Parents said that it could be difficult to get help from either of these. In particular, they said it could be

	hard to get the help or money they needed to stay in touch with their child when they were in residential schools all year. These could sometimes be far away from home so parents needed money to travel there and stay overnight.
SM9	**When services are designed well, with parents, this can make them better** Two UK studies of what people think Challenging Behaviour Foundation (2015 −), a process evaluation (n= 5 services) and McGill et al. (2006 ++), a survey (n=87), talked about the way services have been designed. They said that this can be helpful if done right. People in 1 case study said that doing things right meant getting parents very involved. Parents here were involved in designing and delivering the service. People thought that made the service better (Challenging Behaviour Foundation 2015 −).
SM10	**Barriers and facilitators to maintaining family life** Two studies of what people think talked about how difficult it is for people to keep a normal family life going. One of these was from Canada (Robert et al. 2015 −), a qualitative study (n=15) and 1 was from the UK (McGill et al. 2006 ++), a survey (n=87). One study said the support for families was poor in 2 ways. Firstly, there was not much of it available. Secondly, if it was available it was not very good. This study said that this was bad because family support could be very helpful. It could help stop children from having to go to residential school all year round (McGill et al. 2006 ++). Parents and families said that it was difficult to have a normal family life when children had learning disabilities and behaviour that challenges. This was because: • it could cost them a lot of money to help their child, or to see their child if they live away from home • they had a lot of other things they needed to do as part of family life • they had to work as well as look after their families. The problem was worse if the family did not have very much money to start with. Or parents did not or could not work. It was also worse if the parents themselves were disabled or had poor health. The services parents were happy with tended to be those ones that helped them keep their normal, daily family life going (Robert et al. 2015 −).
SM11	**Finding your way around services** Two studies of what families, parents and professionals think said that it is difficult for people to find their way around services. They said this was a bad thing that can stop people getting the help they need La Valle (2015 −), a qualitative study (n=61 parents/carers; n=128 practitioners)and McGill et al. (2006 ++), a survey (n=87). Professionals in 1 study said that they did not think that there were clear pathways for different children of different ages (La Valle 2015 −). This meant that people are not clear who should do what and when, to help children with different needs in different parts of the local community. People in another study said that professionals did not know what residential schools are available to help children in their area. They also did not know what sort of residential support is right for children. This meant that parents had to try to work things out for themselves. This could be

	difficult without help or advice and could also mean children go to a school that is not right for them (McGill et al. 2006 ++).
SM12	**Respite care and short breaks for children** Three UK studies of what people think talked about respite care for children Challenging behaviour Foundation (2015 −), a process evaluation (n= 5 services), La Valle (2015 −), a qualitative study (n=61 parents/carers; n=128 practitioners)and McGill et al. (2006 ++), a survey (n=87). Two studies said that if children were ‘excluded’ from school (not allowed to go back there) they could be excluded from respite care too (Challenging Behaviour Foundation 2015 −; McGill et al. 2006 ++). It could be that there is no respite care for children with behaviour that challenges. This could be part of the reason that some children had to go far away to residential school (Challenging behaviour Foundation 2015 −). Parents could find respite care very useful. It could also be very difficult for them to get to use it. It could also be the case that respite care was variable in quality – this meant that some was very good and some was bad (McGill et al. 2006 ++). Only a small number of parents in 1 study were happy with their short breaks service. This was because it was not near where they lived and they didn’t think it was very good (La Valle 2015 −).
SM13	**Access to services for children** Two UK studies of what people think talked about how to access services for children Challenging behaviour Foundation (2015 −), a process evaluation (n= 5 services) and La Valle (2015 −), a qualitative study (n=61 parents/carers; n=128 practitioners). One Canadian study also looked at this Robert et al. (2015 −), a qualitative study (n=15). One study said that people may be able to get to the right sort of help more easily if they had intensive, child-focused one-to-one support. ‘Intensive’ means a lot of help given over a short period of time. ‘Child-focused’ means that the people giving help to the family always think about what is going to be best for the child. ‘The idea is that the professional then knows exactly what help the child and family needs. The family can then get the service which offers that help (Challenging Behaviour Foundation 2015 −). One study showed that children often got help when they were older, even though behaviour that challenges often starts in early childhood (La Valle 2015 −). This study also showed that people often do not get specialist help for their child until at least 12 weeks after they asked for help. This study also found that lots of people thought services were useful, but not many actually got to use them. In 1 study, parents said that decisions were made about which services they could get help from based on ‘diagnostic criteria’ (Robert et al. 2015 −). This means that things to do with their child’s health were being used to say whether they could use a service or not. Sometimes they were not able to use a service because of this, but they did not understand why.
SM14	**Understanding whether models of service delivery for adults is effective overall** One high quality systematic review (Balogh et al. 2016 ++) of randomised controlled trials (n=347 total in 7 trials) found that a model of care that included community-based specialist behaviour therapy may slightly decrease behavioural problems and may make no or little difference to costs.

	However the review found uncertain evidence whether increasing the frequency and intensity of intensive community support services decreased behavioural problems. Increasing the intensity of a service probably makes little difference to the burden on carers and little to no difference to costs. There was uncertain evidence that assertive community outreach compared to hospital treatment decreased behavioural problems or decreased the burden on carers. It was also uncertain whether assertive community outreach treatment decreased costs.
SM15	**Staff do not always have the right knowledge, skills and qualities to provide good care** Five studies of what people think talked about the staff helping adults with learning disabilities. Four of these were UK studies Evans and Gore (2016 +) was a qualitative study (n=17); Hatton et al. (2010 ++) was a qualitative study (n=14 family carers); Stenfert Kroese and Rose (2011 +) was a qualitative study (n=16 service users; n=38) staff); National Development Team for Inclusion (2015 +) was a qualitative study (n= 66); and 1 was a systematic review (Griffith et al. 2013 ++) (n=17 studies). People were often unhappy with how little expert knowledge staff had. They thought staff needed training themselves or they needed to be able to bring in specialists in learning disabilities. They also said that when staff didn’t know enough, this could lead to bad outcomes for the person with learning disabilities. There can be a lot of differences between how different staff provide care. Some are better than others. Some know more and some know less. This means that people’s experiences can be very different. People can have bad experiences when staff are off sick, or leave their jobs. Sometimes they are not replaced. Other times there are lots of different staff involved and this can also be difficult. People want to be able to get to know the people working with them, and build trust. Related to this, it is important that staff behave in the right way. They should listen to people and show they care. Evans and Gore (2016 +) explores what staff behaviours people with a learning disability and behaviour that challenges like and don’t like. Participants in the Evans and Gore study didn't like being controlled by support staff. Some people said that the way staffing was arranged had nothing to do with their needs. Some people said that having too much staff support was intrusive and controlling.
SM16	**What helps make sure staff have the right skills and attitudes?** Two moderate quality UK studies of what people think talked about how to make sure you have staff that can help in the right way Stenfert Kroese and Rose (2011 +), a qualitative study (n=16 service users, n=38 staff) and National Development Team for Inclusion (2015 +) a qualitative study (n= 66). Evidence on this was also provided by a high quality systematic review of what caregivers think (Griffith et al. 2013 ++) (n=17 studies). These studies suggested that to make sure services have the right staff in place, they could:

	- be clear in job adverts about what specialist expertise they need and what they should be like as people - make sure they have the right training when they start, and throughout their time doing the job check on how well staff are doing the job, regularly - make sure staff know how to spot problems early so they can help people before they get worse - make sure staff know what it means to work in a way that puts the person first - give staff training in behaviour that challenges - recognise the importance of building trust with people – this takes time because when people lose trust in a staff member or service it is hard for them to get it back and when staff change a lot it can be hard to build trust.
SM17	**Involving families in care planning** Two moderate quality UK studies of what people thing talked about how to involve families in planning Stenfert Kroese and Rose (2011 +) a qualitative study (n=16 service users, n=38 staff); and National Development Team for Inclusion, (2015 +) a qualitative study (n= 66). It is important to work in a way that supports the person and their family, where this is helpful. Services should understand that some families want a lot of help and others do not. People working with families should find out how much they need and want. People working with families should also treat them as equals. They should help families get involvement and make decisions. Families should have power and a say on a day-to-day basis.
SM18	**Deciding which services to put in place** Two moderate quality UK studies of what people think talked about how services need to be arranged: Stenfert Kroese and Rose (2011 +) a qualitative study (n=16 service uses, n=38 staff); and National Development Team for Inclusion, (2015 +) a qualitative study (n= 66). The Stenfert Kroese and Rose study said that: - Sometimes it would be better if services review the help people need together rather than separately. The times it would be useful to do this is if the person has 'borderline' learning disabilities, mental health, substance abuse and/or forensic eligibility criteria' (NDTi 2015: 22). This means they may have some symptoms or be at particular risk of developing these problems. - People should work together in 'virtual teams'. This means they are part of a same team but may not sit in the same office or organisation. They work with each other by email or phone, for example. The NDTi study said families want local, small and specialist hospital care close to their homes. They also want the help people get in hospital to be joined up with the help they get outside of hospital. The study also said there should be 'small, local, low stimulation accommodation for people with complex needs and challenging behaviour' (NDTi 2015: 22). This means their family and friends can keep seeing them. The staff helping them in these places should understand what they need.

SM19	**Being able to get to support services** Four studies talked about how adults can actually get to use support. One of these was a high quality study: Hatton et al. (2010 ++) (n=14 family carers). Two were moderate quality, Stenfert Kroese and Rose (2011 +), a qualitative study (n=16 service users, n=38 staff); and National Development Team for Inclusion (2015 +), a qualitative study (n= 66); and 1 was low quality, Hassiotis et al. (2015 −), a mixed methods study (n=65). Studies said that it was very difficult for people to get help. They often did not know about it. When they did it often was not what they need. This was because it was not available for the right amount of time or at the right time. A number of services in particular were said to be very difficult to access. These were: • General mental health services for people with learning disabilities seemed to be very difficult. These services might be, for example, memory clinics or psychological services (Hassiotis et al. 2015 −; Stenfert Kroese and Rose 2011 +). • Support from CAMHS, speech and language and occupational therapy, social workers and psychologists. Often the waiting lists are over a year long (NDTi 2015 +). Staff in the Hassiotis et al. study (2015 −) also said that they thought there should be more intensive support teams – so people who can provide a lot of help in a short space of time. They also said staff from different services should work together better to help make sure people can get into the services they need.
SM20	**What helps and does not help services working together** Three UK based studies of what people think talked about services or staff working together. One was a low quality mixed methods study (Hassiotis et al. 2015 −), (n=65); 2 were moderate quality qualitative studies (Stenfert Kroese and Rose 2011 +; n=16 service users, n=38 staff; National Development Team for Inclusion 2015 +, n= 66). Families and staff agreed that, overall, lots of services do not work very well together at the moment. It is also different from 1 place in the country to another. In some places services try to join up better than in others. Sometimes services argue about what is best for the person, or who should pay. This can mean families end up having to sort things out for themselves. Staff agreed that services need to work together to be able to do what is needed when people have a crisis. They should also be prepared to step in and take action, not pass people on to another service. This can mean people don't get help at all. One example of how to make sure this happens was to use a care plan (Stenfert Kroese and Rose 2011 +).
SM21	**Looking after people's physical health and wellbeing** Two UK studies talked about how important it is to make sure both people using services and their families stay well and that this does not always happen. One study was high quality qualitative study, Hatton et al. (2010 ++) (n=14 family carers) and 1 was a moderate quality qualitative study (National Development Team for Inclusion 2015 +) (n= 66).

	Family carers from majority and minority backgrounds said they feel they should be able to cope. In fact they often had bad health and were very worried about the person they care for (Hatton et al. 2010 ++). Sometimes the health of people who go into hospital can get worse. All the families in the National Development Team for Inclusion study (2015 +) said that inpatient support was not good for their relative. They said too that sometimes staff do not understand what is the real cause of their relative's problem. For example, they may blame things on the learning disability when really it is because of something else.
SM22	**Looking after people's physical health and wellbeing** Two studies talked about people feeling cut off from others, or ignored. One was a high quality systematic review of views (Griffith et al. 2013 ++, n=17 studies). The other was a moderate quality study (Hatton et al. 2010 +, n=14 family carers). People can feel lonely even when they are in a place where there are other people, like a group home. This can be because they do not feel that they are treated as human beings, with views of their own and things they want' (Hubert and Hollins 2006 (n=20) cited in Griffith et al. 2013). Family carers from majority and minority backgrounds said they can feel very alone. Sometimes they did not want to ask for the help they needed. Sometimes they got help from neighbours or friends and this made them feel better (Hatton et al. 2010 +).
SM23	**Timing of access to support** Three moderate quality studies: Christopher and Horsley (2015 +), a qualitative process evaluation (n=19); Inchley-Mort and Hassiotis (2014 +), a qualitative study (n=6 service users, n=25 carers); and McKenzie and Paterson (2010 +), a process evaluation (n=24),included reports from participants about how to improve access to services. They suggested that services should: • take referrals over the phone, • be available unsociable hours, and • do more follow-up after discharge. When services are not available at the time they are needed, people get disappointed because this is not what they expect (Inchley-Mort and Hassiotis 2014 +). An example of this is when carers call services many times and staff do not get back to them. People have different abilities and demands on their time. Sometimes they can be asked to meet face to face too much. They need different ways to stay in contact with services, for example, face to face, email and phone. This is so they know that support is always there in between the appointments if they had any concerns. McKenzie and Paterson reported that 'The average Assertive Outreach Team waiting time was on average 2.6 days (range 0–19 days)' (p38). People thought this was accessible and meant they could get intensive input when it was needed.
SM24	**Staff skills and knowledge – personal qualities of staff** Christopher and Horsley (2015+), a qualitative process evaluation (n=19) and (McKenzie and Paterson (2010 +), a process evaluation (n=24), talked about the personal qualities of staff in services that worked well. Participants in Christopher and Horsley's study said it worked well when staff were pleasant, person-centred, empathic, approachable and flexible. Other professionals appreciated it when staff were happy to work together

	and ‘Not robotic, they actually care about the clients and have hands on experience’, (quote from private service provider manager in Christopher and Horsley 2015 +). McKenzie and Paterson (2010 +) talked to staff who worked with the assertive outreach team. They said things that helped deliver the service well were when staff had the right skills and knowledge to do their jobs. They also saw staff in this team as professional, objective and helpful. Evans and Gore (2016 +), a qualitative study (n=17), explores what staff behaviours people with a learning disability and behaviour that challenges like and don’t like. Participants in Evans and Gore's study valued support workers being nice or kind and who also helped them do things when they could not do things themselves. Some people liked practical help, while others like emotional support or help when they got angry or upset. Participants also thought that support workers should know them well and appreciated it when support staff made time for them, to talk or made time to be available to give support. Participants didn't like being controlled by support staff. Some people said that the way staffing was arranged had nothing to do with their needs. Some people said that having too much staff support was intrusive and controlling.
SM26	**Joint working** The Christopher and Horsley study (2015 +), a qualitative process evaluation (n=19), reported that ‘joint working’ was important for the behavioural support team working well. They also said that the service worked well when staff were supportive and took into account the family’s point of view. They said the service worked well when staff understood the pressures that can come from day-to-day working with behaviour that challenges. People appreciated it most when staff listened and delivered the service in a flexible way, making all reasonable adjustments. The McKenzie and Paterson study (2010 +), a process evaluation (n =24), asked other services how well they thought the assertive outreach team were doing. Joint working was seen as useful overall. Working together included attending the learning disability team meetings.
SM27	**Active support increases staff knowledge and job satisfaction** Two low quality UK studies Beadle-Brown et al. (2008 −), a process evaluation (n= 29) and Mansell et al. (2008 −), a comparison evaluation (n= 359 adults and 354 staff) looked at person-centred active support in group care homes. The studies tried to find out how it was put in place and what it involved. Both studies reported an increase in staff knowledge and job satisfaction as a result of this approach. In addition, Mansell found that staff who were trained in this approach were more likely to say that behaviour that challenges was caused by a need for stimulation, than bad behaviour people had learned.
SM28	**Behaviour supports at home – preventing out of area placements** Two UK studies of mixed quality Ayres and Roy (2009 −), a process evaluation (n= 26 adults) and McGill et al. (2010 +), a qualitative study (n=unspecified), reported that putting in place support for emergencies supports can prevent out of area placements.

	In Ayres and Roy (2009 −) a supported living outreach team prevented placement breakdown. This led to fewer admissions to hospital and fewer out of area placements. McGill et al. (2010 +) found that a lack of emergency support can lead to out of area placements. This was because there were no local providers able to provide suitable services at the time needed. The lack of suitable providers in a local area providers meant that commissioners continued to use the out of area placements. They did this because it was what they were used to. Once people using services move out of area, they (or their families) are often not keen to move back to the local area. This can be because it is disruptive to move again, or because they have experienced local placement failures before.
SM29	**Better quality social care prevents and reduces behaviour that challenges** There was a small amount of high quality evidence from 1 UK randomised controlled trial (McGill et al. unpublished ++), (n=81 adults with learning disabilities; n=270 staff) about the value of social care to people using services. This study found that improving the quality of social care does make a positive difference for people with behaviour that challenges. They found that it was important to set goals to achieve higher standard of social care and to hold regular reviews of progress. Services should also develop protocols that describe how things will be done. They should also have written documentation makes clear what people can expect from the service and that shows how staff will link with other services for professional advice and support.
SM30	**Better quality social care increases staff satisfaction** There was a small amount of high quality evidence from 1 UK randomised controlled trial (McGill et al. unpublished ++), (n=24 settings) about the value of social care for staff. This study found that improving the quality of social care people helps staff feel more satisfied, and reduces their stress over time.
SM31	**Moving from long stay hospitals to the community – impact on family life** There was a small amount of evidence from 1 moderate quality quasi-experimental study (Perry et al. 2011 +), (n=19), that moving from long stay hospitals to purpose built homes in the community increases family contact over time.
SM32	**Moving from long stay hospitals to the community – impact on community participation** There was a small amount of evidence from 2 mixed quality UK studies Baker (2007 −), a quasi-experimental study (n=60) ; Perry et al. (2011 +), a quasi-experimental study (n=19),about what helps people take part in their communities. Perry et al. found that moving from long stay hospital to purpose built homes in the community increases social activities. The UK views study (Baker 2007 −) said that it helps if you have an individual plan. This should include the types of activities, goals and timelines decided at the beginning to make this happen.
SM33	**Evidence: moving from long stay hospitals to the community**

	Two low quality UK studies - one qualitative study by the National Development Team for Inclusion (2015 +) (n= 66) and a process evaluation by Shared Lives Plus and Keyring (2012 −) (n=unspecified), said that it helps if people who are moving from long stay hospitals to community residential homes have an advocate to help people know what their options are, including knowing about personal budgets.
SM34	**Supporting placements: organisational factors** Two UK studies reported that homes where the community residential placement had lasted were more likely to have better supported staff: . Broadhurst and Mansell (2007 +) a qualitative study (n=39 managers, control group n=20, intervention group n=19); Phillips and Rose (2010 +), an observational, correlational study (n=43). It helped to have access to external professional help advice and support. Placements that lasted were more likely to have written guidance on how to support people in activities, and their developmental goals (Broadhurst and Mansell 2007 +). On the other hand homes where the placement had broken down had: • less effective administrative systems • less staff resources • staff had less energy to implement interventions • poorer physical environments • poorer social environments (the amount of staff contact, assistance and interaction styles). One process evaluation (McKenzie and Paterson 2010 +) was relevant here. This study was of a service that aimed to support people whose community placement was at risk of breaking down. It found that staff skills and professionalism were important parts of the service. Staff needed the time and skills to work in partnership with carers and other professionals. When staff had only limited knowledge, or were not very good at talking to people, this got in the way of the service working as well as it should.
SM35	**Supporting placements – people particularly at risk of placement breakdown** Two moderate quality UK studies Broadhurst and Mansell 2007+, Phillips and Rose 2010+) said that people more at risk of their community residential placement breaking down are those who: • have higher levels of intellectual functioning and demonstrate antisocial behaviour • demonstrate inappropriate sexual behaviour.
SM36	**Supporting placements – prevention of placement breakdown prevents out-of-area placements** Three low quality studies looked at how to support people in their own homes. One study (Ayres and Roy 2009 −), a process evaluation (n= 26), looked at how a supported living outreach team can support families in their home. It found that this can prevent the breakdown of placements that can lead to hospital admission and out-of-area placement. McKenzie and Paterson (2010 −), a process evaluation (n=24),report that a similar service – an assertive outreach team – can support a person in their own environment. This study showed that this can prevent crisis from happening in the first place and so prevent out of area placements. Toogood et al. (2015 −), a process evaluation (n=not specified), found that specialist challenging behaviour support teams can help people who have

	been sent out of area. They did this by bringing them back into local, better quality residential care that prevents future placement breakdown and out of area placement. The study suggested that services need to be made up of personalised packages tailored to the individual that will be affordable and will last.
SM37	**Pathways to alternative residential care – supporting families to prevent alternative residential placements** There was a small amount of evidence from 1 high quality UK qualitative study (Albortz 2003 ++) (n=18), and 1 low quality single group before and after pilot study (Reid et al. 2013 −) (n=11), about providing alternatives to residential care. These studies showed that supporting families could prevent young people being placed in alternative residential care. The Albortz study reported that families most often chose alternative care because of the stress and strain they felt, not because it was the right time to move home. Families said that they didn't have access to the right service to help them. They said this built up over time until they felt that they couldn't cope any longer. Sometimes other family stresses, like divorce or illness meant they were less likely to cope in the long run. The study by Reid et al. (2013−) found that providing short breaks could help prevent residential placements for young people at risk of moving to residential care. These could include, for example, family link foster carers who took the young person into their own home for an overnight stay. They also suggested that families may be less likely to choose residential care if there are: • agency staff who are properly trained to work with families in the home • more directly paid agency staff available. Families supported with a functional behavioural assessment and an individualised positive behavioural support plans helped keep young people in the family home. Whole network training also helped. This means that all the people who are important to the person with learning disabilities and behaviour that challenges are helped to make sure the positive behavioural support plan was implemented properly.
DS01	**What works with funding** This evidence statement is based on expert witness testimony from a case study of services in Devon (comprising testimony from a commissioner, a provider from a charity that supports people with learning disabilities, and the mother of a young women with learning disabilities who had previously displayed behaviour that challenged services). The testimony stated that part of the success of the service is because local funding arrangements have enabled providers to have quick access to 'contingency funds' if a person's behaviour deteriorates and they require extra support, rather than the provider having to wait for additional funding from the commissioner. This meant they could act quickly to prevent a more restrictive placement or admission to hospital. The testimony stated that the provider uses third party individual service funds, funded through their personal health budget programme. This commissions not only the direct support but also has a contingency amount of funding to be used for "what if" scenarios, and up front recruitment training and induction of staff.
DS02	**Multiagency working** This evidence statement is based on expert witness testimony from a case study of services in Devon (comprising testimony from a commissioner, a

	provider from a charity that supports people with learning disabilities, and the mother of a young women with learning disabilities who had previously displayed behaviour that challenged services). The testimony emphasised the importance of having a mature and trusting relationship between commissioners and providers. Key features of this included: • Focusing on outcomes • Commissioners paying in advance for services using a payment card. If the core provider team decides that they want to change the style and shape of direct support that is permissible. • This flexibility also avoids the need for repeated requests to funding panels from care management staff- it ensures a prompt response when change is needed and reduces the transactional time and effort for administrative and care staff. The testimony stated that relationships with other agencies were also important in ensuring a good service, especially with the police and criminal justice system, housing, and primary and acute healthcare.
DS03	**Staff skills and knowledge in support services** This evidence statement is based on expert witness testimony from a case study of services in Devon (comprising testimony from a commissioner, a provider from a charity that supports people with learning disabilities, and the mother of a young women with learning disabilities who had previously displayed behaviour that challenged services). The experts stated that staff must understand the complex behaviours of people, including being able to anticipate people's individual triggers, avoid distressing situations, and have the energy and interests to engage people in the things they like to do. The expert witnesses stated they believed it worked well if staff were chosen to work with someone when they have the right temperament, values and shared interests and hobbies that will help that person develop and grow.
DS04	**Invest to save** This evidence statement is based on expert witness testimony from a case study of services in Devon (comprising testimony from a commissioner, a provider from a charity that supports people with learning disabilities, and the mother of a young women with learning disabilities who had previously displayed behaviour that challenged services). The expert witnesses for Devon stated that over time, as people form 'real' relationships with people not paid to be with them, they were able to safely reduce support, creating some savings. They thought this was important as initial bespoke services are often not cheaper than hospital care. They found that the savings take time to show in the system, but are made in the long run. The expert witnesses suggested that a long-term view is needed, and to be realistic about how long it can take to help people feel fully settled after long periods in hospital.
DS05	**Bespoke services, not one size fits all** This evidence statement is based on expert witness testimony from a case study of services in Devon (comprising testimony from a commissioner, a provider from a charity that supports people with learning disabilities, and the mother of a young women with learning disabilities who had previously displayed behaviour that challenged services). The expert witnesses stated that the approach that had worked well for them was to work with people as individuals and deliver a bespoke service.

	Their view was that it was most effective to work with the person and their family to produce an Individual Service Design (ISD), and then put this ISD into practice. This would include the use of a Personal Health Budget (PHB) or by using the PHB as an Individual Service Fund (ISF).
DS06	**Safe and stable accommodation** This evidence statement is based on expert witness testimony from a case study of services in Devon (comprising testimony from a commissioner, a provider from a charity that supports people with learning disabilities, and the mother of a young women with learning disabilities who had previously displayed behaviour that challenged services). The expert witness said that they believed that stable accommodation, including through home ownership, is critical to the success of their local model. They emphasised the importance of separating provision of accommodation and support.
DS07	**Types of accommodation** This evidence statement is based on expert witness testimony from a case study of services in Devon (comprising testimony from a commissioner, a provider from a charity that supports people with learning disabilities, and the mother of a young women with learning disabilities who had previously displayed behaviour that challenged services). It was the expert witness' experience that group care is often not suitable for the people with whom they work, and individual accommodation often better meets people's needs and maintains stability. The expert witness stated that it can be difficult to adequately tailor the environment to meet the person's needs if there are several people living in that environment.
DS08	**Making the right use of inpatient services** This evidence statement is based on expert witness testimony from a case study of services in Devon (comprising testimony from a commissioner, a provider from a charity that supports people with learning disabilities, and the mother of a young women with learning disabilities who had previously displayed behaviour that challenged services). The expert witnesses stated that in their experience it is difficult for inpatient services to be effective unless they are provided for a short period of time and are treatment focused. Treatment would include medication and also therapeutic activities based on real skills learning and good social and leisure activities. The expert witnesses thought that inpatient services were usually more effective when they focused rehabilitation and were very clear about the route to discharge, and when they work in partnership with the person and their family and any community supports that person may have.
TC01	**Personal health budgets and Education, Health and Care plans are helpful levers to implement a good service model** This evidence statement is based on expert witness testimony of current good practice seen in Transforming Care pilot area programmes (provided by a representative from the Transforming Care Partnership Board and a lead clinical practitioner on the Transforming Care board). The testimony stated that PHBs & EHC plans and Annual Health Checks can be helpful levers for change. These were seen as helpful to inform people as to why it is necessary to see things change but also helpful to know what levers (the things people must do if they want to get paid for example) are available to make change happen

TC02	**Quality assurance** This evidence statement is based on expert witness testimony of current good practice seen in Transforming Care pilot area programmes (provided by a representative from the Transforming Care Partnership Board and a lead clinical practitioner on the Transforming Care board). The expert witness testimony stated that it was important to – 'measure what you value, not value what you measure' – by asking people what is important to them locally, regionally, and nationally.
ECU1	**Housing and support options** There is limited evidence from 1 low quality review on the costs and cost-effectiveness of different housing and support models for people with learning disabilities (Harflett et al. 2017−), a systematic review (n=unspecified). The review finds that the evidence on costs and cost-effectiveness of different housing and support models is unclear based on current available research.
ECU4	**Specialist behaviour therapy team** There is limited evidence from 1 small (n=63) UK randomised, single blind study (Hassiotis et al. 2009+) that referring adults with intellectual disabilities and challenging behaviour to a specialist behaviour therapy team (using applied behavioural analysis) plus standard care, compared to standard care alone, is more effective in improving levels of challenging behaviour and reducing the likelihood of a comorbid mental health organic disorder over a 6-month period. This study also found that net costs for intervention and control groups were not statistically different, although the intervention group was trending towards lower total costs (taking the perspective of health and social care service use, as measured over a 6-month period). This study is applicable to the UK context. It has some potentially serious limitations given that the time horizon was too short in order to detect the full changes in service use and costs. With a longer time horizon, we might expect to see statistically significant cost savings as a result of better outcomes for the intervention group on both challenging behaviour and mental health.
ECU5	**Positive behavioural support for adults** There is evidence on the use of positive behavioural support for adults from 1 good quality matched comparison UK study (Inchley-Mort 2014, ++) (n=46), and 1 economic modelling study from the UK with potentially serious limitations (Iemmi et al. 2015) (n=5). Due to the lack of robust study designs we cannot conclude whether positive behavioural support is or is not cost-effective.
ECU6	**Positive behavioural support for children and adolescents** There is evidence on the use of positive behavioural support for children and adolescents from 1 economic modelling study from the UK with potentially serious limitations Iemmi et al. 2016) (n=12). Due to the lack of robust study designs we cannot conclude whether positive behavioural support is or is not cost-effective.
ECU8	**Supported living outreach** There is evidence on the use of supported living outreach for adults with severe psychiatric, behavioural, and forensic needs from 1 low quality process evaluation from the UK (Ayres and Roy 2009, −), a process

	evaluation (n= 26 adults). Due to the lack of robust study designs we cannot conclude whether this is or is not cost-effective.
ECU9	**Individual budgets** There is evidence on the use of individual budgets for adults with learning disabilities in inpatient settings from 1 economic modelling study from the UK with potentially serious limitations (Department of Health 2015), (n=not relevant). Due to the lack of robust study designs we cannot conclude whether this is or is not cost-effective.

For Guideline Committee discussion of the evidence see the Evidence to Recommendations tables in Section 3.7.

Included studies for these review questions

Ahmad F et al. (2002) Partnership for developing quality care pathway initiative for people with learning disabilities: part I: development. Journal of Integrated Care Pathways 6, 9–12

Alborz A (2003) Transitions: Placing a son or daughter with intellectual disability and challenging behaviour in alternative residential provision. Journal of Applied Research in Intellectual Disabilities 16, 75–88

Ayres M, Roy A (2009) Supporting people with complex mental health needs to get a life! The role of the supported living outreach team. Tizard Learning Disability Review 14(1), 29–39

Baker PA (2007) Individual and service factors affecting deinstitutionalization and community use of people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 20, 105–9

Balogh R, McMorris CA, Lunsky Y et al. (2016) Organising healthcare services for persons with an intellectual disability. Cochrane Database of Systematic Reviews 4: CD007492

Barron D, Hassiotis A, Paschos D (2011) Out-of-area provision for adults with intellectual disabilities and challenging behaviour in England: policy perspectives and clinical reality. Journal of Intellectual Disability Research 55, 832–43

Beadle-Brown J, Hutchinson A, Whelton B (2008) A better life: the implementation and effect of person-centred active support in the Avenues Trust. Tizard Learning Disability Review 13, 15–24

Beadle-Brown J, Mansell J, Cambridge P et al. (2010) Adult protection of people with intellectual disabilities: incidence, nature and responses. Journal of Applied Research in Intellectual Disabilities 23, 573–84

Bigby C, Beadle-Brown J (2016) Improving quality of life outcomes in supported accommodation for people with intellectual disability: what makes a difference? Journal of Applied Research in Intellectual Disabilities, advance online publication: doi:10.1111/jar.12291

Broadhurst S, Mansell J (2007) Organizational and individual factors associated with breakdown of residential placements for people with intellectual disabilities. Journal of Intellectual Disability Research 51, 293–301

Buxton L, Pidduck D, Marston G et al. (2004) Development of a multidisciplinary care pathway for a specialist learning disability inpatient treatment and assessment unit. Journal of Integrated Care Pathways 8, 119–26

Challenging Behaviour Foundation (2015) Paving the way: How to develop effective local services for children with learning disabilities whose behaviours challenge. Chatham: Challenging Behaviour Foundation

Christopher R, Horsley S (2015) An evaluation of a behavioural support team for adults with a learning disability and behaviours that challenge from a multi-agency perspective. British Journal of Learning Disabilities, advance online publication: doi:10.1111/bld.12137

Department of Health (2015) Securing inclusion and independence for all: impact assessment. London: Department of Health.

Devapriam J, Alexander R, Gumber R et al. (2014) Impact of care pathway-based approach on outcomes in a specialist intellectual disability inpatient unit. Journal of Intellectual Disabilities 18(3), 211–20

Evans T, and Gore N (2016) Staff behaviours valued by service users: views of people whose behaviour challenges. International Journal of Positive Behavioural Support 6(2), 4-11.

Griffith GM, Hastings RP (2014) ‘He's hard work, but he's worth it’. The experience of caregivers of individuals with intellectual disabilities and challenging behaviour: a meta-synthesis of qualitative research. Journal of Applied Research in Intellectual Disabilities 27(5), 401–19

Griffith GM, Hutchinson L, Hastings RP (2013) ‘I'm not a patient, I'm a person’: The experiences of individuals with intellectual disabilities and challenging behavior – A thematic synthesis of qualitative studies. Clinical Psychology: Science and Practice 20, 469–88

Hassiotis A, Guinn A, Tanzarella M et al. (2015) Community-based services for people with intellectual disability and mental health problems: literature review and survey results. London: Royal College of Psychiatrists

Hassiotis A, Robotham D, Canagasabey A et al. (2009) Randomized, single-blind, controlled trial of a specialist behavior therapy team for challenging behavior in adults with intellectual disabilities. The American Journal of Psychiatry 166, 1278–85

Hatton C, Emerson E, Kirby S et al. (2010) Majority and minority ethnic family carers of adults with intellectual disabilities: Perceptions of challenging behaviour and family impact. Journal of Applied Research in Intellectual Disabilities 23, 63–74

Iemmi V, Knapp M and Brown F (2016) Positive behavioural support in schools for children and adolescents with intellectual disabilities whose behaviour challenges: an exploration of the economic case. Journal of Intellectual Disabilities 20(3), 281-295.

Iemmi V, Knapp M, Saville P et al. (2015) Positive behavioural support for adults with intellectual disabilities and behaviour that challenges: an initial exploration of the economic case. International Journal of Positive Behavioural Support 5, 16-25.

Inchley-Mort S, Hassiotis A (2014) Complex behaviour service: content analysis of stakeholder opinions. Advances in Mental Health and Intellectual Disabilities 8, 228–36

Inchley-Mort S Rantell K, Wahlich C et al. (2014) Complex Behaviour Service: enhanced model for challenging behaviour. Advances in Mental Health and Intellectual Disabilities 8(4), 219-227

James N (2013) The formal support experiences of family carers of people with an intellectual disability who also display challenging behaviour and/or mental health issues: what do carers say? Journal of Intellectual Disabilities 17(1), 6–23

La Valle I (2015) Services for children with learning disabilities whose behaviours challenge: A survey of families' and professionals' experiences. Chatham: Challenging Behaviour Foundation

Mansell J, Beadle-Brown J, Whelton B et al. (2008) Effect of service structure and organization on staff care practices in small community homes for people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 21, 398–413

McGill P, Cooper V, Honeyman G (2010) Developing better commissioning for individuals with behaviour that challenges services: a scoping exercise. Canterbury: Tizard Centre

McGill P, Tennyson A, Cooper V (2006) Parents whose children with learning disabilities and challenging behaviour attend 52-week residential schools: their perceptions of services received and expectations of the future. The British Journal of Social Work 36, 597–616

McGill P, Vanono L, Clover W et al. (unpublished) Preventing the challenging behaviour of adults with complex needs in supported accommodation

McKenzie K, Paterson M (2010) Evaluating an assertive outreach team for supporting clients who present behaviour that challenges. British Journal of Learning Disabilities 38, 319–27

National Development Team for Inclusion (2015) Informing the service model: a report about the experiences of people with learning disabilities and families. Bath: National Development Team for Inclusion

Perry J, Felce D, Allen D et al. (2011) Resettlement outcomes for people with severe challenging behaviour moving from institutional to community living. Journal of Applied Research in Intellectual Disabilities 24(1), 1–17

Phillips N, Rose J (2010) Predicting placement breakdown: Individual and environmental factors associated with the success or failure of community residential placements for adults with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 23, 201–13

Reid C, Sholl C, Gore N. (2013) Seeking to prevent residential care for young people with intellectual disabilities and challenging behaviour: examples and early outcomes from the Ealing ITSBS. Tizard Learning Disability Review 18, 171–8

Robert M, Leblanc L, Boyer T (2015) When satisfaction is not directly related to the support services received: understanding parents' varied experiences with specialised services for children with developmental disabilities. British Journal of Learning Disabilities 43, 168–77

Shared Lives Plus and KeyRing (2012) Closing the Winterbournes. Liverpool: Shared Lives Plus

Stenfert Kroese B and Rose JL (2011) Mental health services for adults with learning disabilities. London: The Judith Trust

Toogood S, Saville M, McLennan K et al. (2015) Providing positive behavioural support services: specialist challenging behaviour support teams. International Journal of Positive Behavioural Support 5, 6–15

3.4 Timely access to services

Introduction to the review question

The purpose of this review was to assess what models of service delivery were effective in helping people to access services when they need them. We also reviewed what people said about their views and experiences of access to services. This review questions was developed from the scope and consultation with stakeholders who said this was important and we know from the systematic review of views and experiences that this can be a problem, especially when people need help at short notice or in a crisis.

Effectiveness studies: we found only 1 randomised controlled trial that looked at whether a liaison worker could improve access to services for families from Bangladeshi and Pakistani communities. One other study used a cross-sectional survey to look at patterns of services use.

Qualitative studies: we found 2 studies that asked people's views of their access to services. One of these was a cross-sectional survey and 1 held interviews with families.

Overall the study quality was mixed. Compared to other study designs, surveys are prone to more sources of bias and are less reliable in their findings. However, they are the best kind of study to answer questions about the current service needs and patterns and trends in service use. We looked for themes where more than 1 study found the same thing. This gave us more confidence in the reliability of the findings than from just 1 study.

Review questions

Q.4. What models of service delivery facilitate timely access to effective and cost-effective services for children, young people and adults with learning disabilities and behaviour that challenges?

Summary of the review protocol

For full protocols see appendices A

Population

People with a learning disability and behaviour that challenges, parents, families or carers of people with a learning disability and behaviour that challenges. Professionals who work with people with a learning disability and behaviour that challenges.

Intervention

Community-based services, inpatient services, models of service delivery.

Setting

All settings where care is delivered.

Person-focused outcomes

Child development outcomes; continuity of care; families and carers stress and resilience; frequency, severity and duration of behaviour that challenges; health and social care-related quality of life; inclusion in community life; service user involvement in planning, delivery and monitoring of services; service user, family and carer satisfaction.

Service-focused outcomes

Availability, access and uptake of local services; equity of access; timely discharge; out-of-area placements; use of inpatient services.

Phenomena of interest (for views and experiences studies)

Barriers and facilitators to access to services; experiences of stress and resilience; preferences and values; involvement in the planning, delivery and monitoring of services; inclusion in community life; independence.

See Appendix A for full protocols.

How the literature was searched

A search strategy for all of the review questions combined was developed and the questions were translated into a framework of 5 concepts of: a) population (people with a learning disability and behaviour that challenges), and b) service provision (including models of services and service capacity) or c) risk management or safeguarding or d) integrated services or e) access to services. These reflected the question areas; types of service provision, service capacity, service delivery and integration of services. The search strategy was run between December 2015 and January 2016 and update searches were conducted between February and March 2017. See Appendix A for full details of the search.

How studies were selected

Results from the searches were stored in EPPI-review 4 a software program designed for information management of systematic reviews. The titles and abstracts of these results were screened against inclusion criteria that was developed from the scope. Two reviewers looked at the same studies titles and abstracts independently of each other and compared their results to make sure that the inclusion criteria was understood and applied in the same way by both reviewers.

Studies that were found to meet the initial inclusion criteria were assigned to the relevant review question and the full text was retrieved for a second screening against the criteria in the protocol.

The review team found 14 studies relevant to this review question based on the title and abstract. These were screened again with the full text and 4 met the inclusion criteria and were included for this review question. Two studies looked at the effectiveness models to improve access to services and 2 were studies about people's views and experiences of services.

See Appendix B for full critical appraisal and findings tables.

Narrative summary of the evidence

Below are the narrative summaries of included studies, including economic and cost-effectiveness studies where identified.

Chadwick O, Beecham J, Piroth N, Bernard S, Taylor E (2002) Respite care for children with severe intellectual disability and their families: Who needs it? Who receives it?

Review question(s): 4

Organisations the authors were involved with:

1. Institute of Psychiatry, Psychology & Neuroscience, King's College London

Type of study: Qualitative study

Country: UK

Population: Parents/family carers of children with severe learning disabilities who are in need of or use respite care services

Type of service: Short breaks, community support, respite care in a local authority home or with another family

Quality score: ++

Study aim

To find out what was different about families who wanted respite care from those who did not. And for those that wanted respite care, what was different about those families who received respite care from those who did not.

Findings

Total 30% of families received respite care. Most respite care was provided in a local authority home, with around 30% provided with another family. Nearly 40% of families that did not receive respite care said it was because they felt they didn't need it. A further 34.4% of this group did not receive respite care because no place was available.

What stops people from getting access to services?

Families did not receive respite care because:

- felt they did not need it (37.3%)
- no place available (34.3%)
- unaware of respite services (19.4%)
- had declined it because they didn't want to accept an overnight placement away from home (8.9%).

There was a strong association with those families unaware of respite services also having no contact with social workers. Families who were unaware of respite care were also more likely to be of African origin or their child's level of functioning was higher.

What distinguished families who wanted and received respite care from those who did not?

- Children who received respite care were as a group older (mean age =8 years 6 months).
- Total 41.9% of them came from families with at least 4 children at home.
- They were significantly more likely to suffer from epilepsy.

However, there wasn't any evidence to suggest that these families felt a greater need for respite care.

What distinguished families who wanted respite care from those who did not?

- More severe behaviour problems in the child.
- More severe stress in themselves.
- They were less likely to have large families.
- They were less likely to speak a language other than English at home.

What needs to happen for people to get better access to services?

There needs to be more access to respite care. Two-thirds of those who had received respite care would have liked to have received more. Families wanted:

- more short respite breaks (40%)
- longer periods of respite (23.3%)
- greater flexibility in the duration of episodes of respite care (10%).

Satisfaction with services

Only 2 families expressed dissatisfaction about the form of respite care which suggests that people were generally happy with the choice of respite care when it was available to them.

Considerations

This is a good study because it looks at both the demand and supply aspects of respite care so we can find out if respite care, where it is available, if is going to the families who feel they need it. It can help us understand some of the factors that might be getting in the way of families receiving respite care. However, we should be cautious when interpreting the results because it is about the population of children with severe intellectual disability receiving services in an inner area of London. We don’t know how many children in the study also exhibited challenging behaviour and if the respire care services provided in this study are similar to how respite care is provided in other locations. While 103 families participated in the study, this was only about half of the sample eligible to participate, so not a high response rate, yet those children that were included in the study were representative of the population of children with severe intellectual disability.

The study shows that where respite care is available, it isn't going to the families that feel they need it. This suggests that services or commissioners need to identify those families with more severe behaviour problems in the child; more severe stress in themselves; and to a lesser extent, families with fewer children that are more likely to speak only English at home to help make sure that respite care is allocated to those that need it.

The findings also suggest that services or commissioners need to improve the variety and supply of respite care placements capable of managing children with more challenging behaviour and to develop more appropriate and acceptable forms of respite care for preschool children and their carers. This includes providing respite care for families of younger children where the parents are less likely to want their child to spend an overnight placement away from home.

Douma JCH, Dekker MC, and Koot HM (2006) Supporting parents of youths with intellectual disabilities and psychopathology

Review question(s): 4

Organisations the authors were involved with:

1. Department of Child and Adolescent Psychiatry, ErasmusMG-Sophia, Rotterdam

2. Department of Developmental Psychology, Vrije Universiteit, Amsterdam

Type of study: Cross-sectional

Country: The Netherlands

Population: Parents/family carers of young people (10–24) with learning disabilities and additional mental health problems

Type of service: Community support: information, practical/material help, mental health care, respite care

Quality score: +

Study aim

The aim of the study was to find out about the specific support needs of parents who perceive emotional and/or behavioural problems in their child with intellectual disability and to find out which needs for support are met; the variables related to both needing and receiving support; and the reasons why parents don't seek help.

Characteristics

The young people in the study were in the age range 10–24. Total 60.9% were male and they all had a mild or moderate intellectual disability; 71.3% past psychopathology; 22.4% had high level physical problems.

For the parents in the study, 56.7% perceived both emotional and behavioural problems in their child, 21.3% only behavioural and 22.0% only emotional problems. Total 21.2% were single parents and 90.7% had more than 1 child in the family.

Compared with the wider study population, families in the sample experienced a problematic relationship between child and parent(s) more often and had significantly more emotional and behavioural problems.

Findings

What are the support needs of parents who perceive emotional and/or behavioural problems?

Most parents (88.2%) needed some type of support because of their child's emotional or behavioural problems. Moreover, 67.4% needed at least 3 different types of support. Parents who perceived both emotional and behavioural problems needed support the most.

The supports most often needed were ‘a friendly ear’ (78.1%), ‘information’ (68%), ‘child mental health care’ (56.7%) and ‘activities’ (50.9%). Parents of children with moderate ID or physical problems especially needed respite care, activities for the child and practical/material help.

It’s interesting that the needs most often reported (‘a friendly ear’ and ‘information’) related to providing the parents with informal or emotional support or advice and were not aimed at directly dealing with their child’s problems.

An interesting finding was that a need for respite care was only identified by 38.9% of parents and met 61.1% of the time. The authors suggest this is relatively low but can be explained by the fact that this need is more often present in parents of youths with more severe ID and younger age (p578).

Also, only 24% of people indicated a need for ‘practical/material help’. The authors suggest that this could be explained by parents’ unawareness of the existence of ‘practical or material help’ or it might also be that this type of support was not their highest priority.

What increased the odds of needing support?

The things that increased the odds of needing any type of support largely represented increased parental stress and include: past psychopathology, parental psychopathology, having parental worries about their child, higher parental educational level and socioeconomic Status (SES), problematic parenting and hostile family functioning.

Which services were met?

The needs for a ‘friendly ear’, ‘respite care’ and ‘information’ (75.3%, 61.1%, 51.3%) were most often met.

Which services were unmet?

The needs for ‘parental counselling’, ‘activities’ and ‘child mental health care’ (64.5%, 61.5%, 59.4%) were most often unmet.

What distinguished parents who received support from those who did not?

This differed for the different types of support.

- Having a high need for support increased the odds of receiving ‘a friendly ear’, ‘respite care’ and ‘child mental health care’.
- Parents who worried most about their child more often received ‘information’.
- Parents of younger children and with a moderate ID more often received ‘activities’.
- Parents who had less problems with parenting more often received ‘practical/material help’.

Parents with a higher SES more often received ‘parental counselling’.

Why don't parents seek support?

The reasons why parents do not seek support, despite an identified need relate to:

- their evaluation of their child’s problems (not so serious or as temporary)
- wanting to solve these problems themselves first, and
- not knowing where to find help.

What needs to happen for people to get better access to services?

Since parents support needs were frequently unmet, as a first step in improving access to support service providers need to become aware of parents’ high level and diverse needs for support. Services also need to:

- Improve access to ‘parental counselling’, ‘activities’ and ‘child mental health care’ the services with the highest unmet demand.
- Consider both the child’s problems and the parents’ and family’s ability to deal with these problems because the stressful circumstances the family are under increases the odds that they will need help.
- Consider how to provide the informal support, such as a ‘friendly ear’ or ‘information’ that families need the most. This could include:
    - providing information about what support is available and where it can be obtained from

- providing more information to parents about child’s problems, how to handle them
- if service providers can’t provide these types of support, help parents get in contact with alterative service providers
- considering how they provide information and how to make it more accessible
- providing a central source of information – the authors suggest that a case manager could act as a central source and help families access support.

Considerations

The main limitation of this study is that it is a Dutch study, so there might be things that are different in the way that they provide services in the Netherlands which effect the types of support needs that families require that are nor present in the UK. However, all the types of support identified in the study are available in the UK.

A good thing about this study is that it focuses on the parent’s perception of emotional or behavioural problems in their child as this is what leads parents to seek help, rather than the assessed problems in the child. This provides a more accurate view of the support needs of this group.

However, there is also a downside that this study only considered the perspective of parents which is where parents have identified barriers to accessing services, for example ‘not knowing where to find help’. While this might suggest that the service provider plays a role in unmet needs for support, for example, through local unavailability, or lack of information, the authors warn that no firm conclusions can be drawn because only the perspectives of parents were included.

Knapp M, Comas-Herrera A, Astin J, Beecham J, Pendaries C (2005) Intellectual disability, challenging behaviour and cost in care accommodation: What are the links?

Review question(s): 2.1, 4

Organisations the authors were involved with:

1. Personal Social Services Research Unit, LSE Health and Social Care

2. Personal Social Services Research Unit, University of Kent

3. West Kent NHS and Social Care

4. Centre for the Economics of Mental Health, Institute of Psychiatry, King's College, London

Type of study: Cross-sectional

Country: UK

Population: Adults with learning disabilities and behaviour that challenges, living in care accommodation in some areas of England – the sample in the study is 930 people

Type of service: Accommodation, general hospital services, day activity services and primary care and community support

Quality score: +

Study aim

To look at the patterns of service use and costs for people with intellectual disabilities and challenging behaviour in care accommodation in some areas of England; and to explore the links of those patterns (p298).

Characteristics

For the costed sample of 930 people, the mean age of service users was 44.4, range 20–92. The level of Intellectual disability was mean 21.9, range 0–42 measured on the Learning Disability Casemix Scale (LDCS). The level of challenging 7.5 mean 0–30, range measured using the same scale.

What needs to happen for people to get better access to services?

Findings

Patterns of service use

The use of services outside residential care reflected the degree of intellectual disability and behaviour that challenges. There was also a sector effect, for example, service users living in NHS settings were more likely to use NHS day hospital services, see a dietician or occupational therapist, but less likely to go to an education centre, drop-in centre of other social club, and also less likely to see a GP.

The utilisation rate of services was as follows.

Hospital

General hospital outpatient 10.4%

General hospital accident and emergency 7.3%

Day activity services

Intellectual disability hospital-based day activity 17.2%

Work-orientated centre 11.1%

Day centre or social club (non-NHS) 39.3%

Education centre 16.9%

Drop-in centre 15.4%

Other day care 29.8%

Primary care and community support

General practitioner 55.7%

Dietician 25.2%

Speech therapist 20.5%

Occupational therapist 22.4%

Psychologist 12.2%

Psychiatrist 20.1%

Hospital-based day activity made the largest contribution to total cost, reflecting both an intensive use as well as a higher unit cost than the other types of day services. Day centres and social clubs were the more widely used day services.

What influences service use?

A number of different factors were found to influence service use including the following.

Level of intellectual disability
The degree of intellectual disability influenced the use of all services. Individuals with more severe intellectual disabilities were more likely to use services such as speech therapy, physiotherapy or hospital-based day activities. Non-hospital-based day activities tended to be used by people with more moderate intellectual disabilities.

Extent of challenging behaviour

The extent of challenging behaviour influenced used of: day centres/social clubs, psychologists, psychiatrists and dieticians.

Age

Other characteristics, such as age, affected the probability of receiving services. Older people were less likely to be offered services such as places at work-oriented centres, or seeing a psychologist or a speech therapist, but more likely to see a GP (p301).

Size of residential home

People in smaller homes were less likely to go to work centres, education centres or drop-in centres, but on the other hand were more likely to go to day centres (p302).

Sector

People living in private/voluntary homes were less likely than people in NHS facilities to use hospital-based day activities, but more likely to go to education centres or drop-in centres, or receive other types of day care. They were also more likely to see a GP, but less likely to see an occupational therapist or dietician (p302).

NHS trusts tended to specialise in providing services for people with more severe level of disability. The mean score on intellectual disability of people living in an NHS home was 25.6 compared with 13.5 for private or voluntary sector. The mean score on challenging behaviour of people living in an NHS home was 8.9 compared with 5.8 for private or voluntary sector.

Cost information

In the costed sample, accommodation was provided by:

7 NHS trusts (66% of people in the sample),

6 private for profit providers (25% of the sample),

1 voluntary or non-profit provider 9% of sample).

The average weekly cost for sample members (£, 1996/97 prices) was £692, which includes averages of: £588 accommodation (and associated staffing); £75 day care; £22 professional or community services; £7 acute healthcare.

Average costs were higher in NHS settings where residents scored more highly on both the intellectual disability and challenging behaviour indicators, which may partly explain the higher costs.

In terms of scale of facility, NHS facilities benefited from economies of scale with cost being just under £2 lower per resident week for each additional resident in the facility. Whereas in the voluntary/private facilities there was ‘diseconomies of scale’, with each additional resident in the home generating an additional cost of £2.48 per resident week across all residents (p303).

Implementation issues

In the context of a national policy commitment to person-centred planning, the study suggest that commissioners need to explore the sources of cost variation between individuals, sectors and types of accommodation in order to meet the policy objectives on quality, choice, independence and inclusion.

Considerations

The sample of people with intellectual disabilities was non-randomly selected and over represented the NHS sector and under-represented the other sectors which makes it difficult to generalise the findings nationally.

You also need to be cautious in drawing conclusions from the cost data. First, the data in the study is from a relatively small number of independent providers. Second, aggregated cost for residential accommodation settings were used and we don't know the extent of which if any service costs might have been included in the accommodation cost so this means the analysis relates only to services not already provided within the accommodation budget. Third, there was a lot of variance in costs which the authors cannot fully explain, however they say 'many other cost studies in the intellectual disability field have attained very similar proportions of variance' (p304).

Raghavan R, Newell R, Waseem F, Small N (2009) A randomized controlled trial of a specialist liaison worker model for young people with intellectual disabilities with challenging behaviour and mental health needs

Review question(s): 4

Organisations the authors were involved with:

1. School of Health, Community and Education, Northumbria University, Newcastle upon Tyne
2. School of Health Studies, University of Bradford
3. Calderdale Council, Halifax, UK

Type of study: Comparison evaluation. Twelve young people were randomly allocated to the treatment group, which had the help of the liaison worker, and 14 young people were allocated to the control group who accessed services on their own. Following the intervention, 2 small focus groups were held with carers and service providers to get their perspectives on the trial

Country: UK

Population: Parents/family carers of young people (13–25) with learning disabilities and behaviour that challenges families from Pakistani and Bangladeshi communities

Type of service: Liaison worker

Quality score: +

Study aim

The aim of this study was to evaluate the effectiveness of a liaison worker in helping young people and their families from Pakistani and Bangladeshi communities access appropriate intellectual disabilities and mental health services. The authors wanted to find out if families receiving input from the liaison worker would have more contact and better outcomes from services.

The role of the liaison worker

Broadly, the role of the liaison worker was to:

- visit and/or telephone participants at least once every fortnight
- provide advice about the availability of particular services and help participants access these services (for example, by helping them with making initial contacts, by discussion of participants' difficulties with appropriate professionals)
- liaise with people providing services, making them aware of the family and young person's needs and discussing how service providers can take action to help them (p259).

Findings

Families receiving input from the liaison worker had more frequent contact (111 liaison, 40 controls) with more services (47 liaison, 17 controls) than did families not receiving this input and had more results (33 liaison, 9 controls) from such contacts.

For the other outcomes measured, there wasn't as much change. There were no differences between the 2 groups on quality of life, participants challenging behaviours or carers mental health. However, there was also some indication that young people with intellectual disabilities had less challenging behaviours following intervention with the liaison than controls. There was also a slight trend toward carers in the 'liaison group' experiencing better physical quality of life.

From the perspective of families and carers, people that got help from the liaison ‘felt better equipped in obtaining contact with appropriate services’ (p262). While the control group felt that they had not progressed much in achieving help during the trial they ‘reported continuing difficulties in gaining necessary access to services, help and support’ (p262).

What needs to happen for people to get better access to services?

The findings from the study and the authors’ observations point to some things that can help people get better access to services, these include:

- Services need to reach out to families that need support. For many of the families in the study it is daunting to seek out and find appropriate help from a wide range of services and professionals, so services need to reach out to families that need help and make the first contact, rather than the other way round. It helps if the liaison worker comes from the same minority ethnic community as the population of service users because they are ‘able to communicate with families using a common language and have a good understanding of the culture norms’ (p262).
- More help with practical things. Families indicated that they need help with practical matters such as making appointments, leisure activities, home improvements required because of the physical disability of the young person, information and advice on benefits.
- Better information about services and types of support. Families indicated that they need more information about how to seek help with challenging behaviour and mental health issues and also what clinical services are available.
- Better information in relation to transition. For young people transiting to adult services, used to schools often referring them to services (Raghavan et al. 2005) there needs to be better information for families on the appropriate referral process for mental health or challenging behaviour services.
- Clearer information about what services are available. Families can have different perceptions on what statutory services can provide. Services and professionals need to be clearer about what is available.

Considerations

The number of families in the study was small and it took place with 1 minority ethnic community. You need to consider whether the intervention or ‘liaison worker’ model would work with other minority groups and also for the majority group to know how generalisable the results from this study can be.

The methods used in this study were good because the authors assigned people randomly to the 2 groups, standardised assessment tools were used, appropriate statistical methods were used to identify differences between the 2 groups and the authors used a number of methods to try to limit bias in the study. However, despite all their efforts there were still some issues with the data collection methods including the liaison worker taking the pre-treatment measurements, instead of someone independent from the study and a reliance on families to report ‘contacts with services’ retrospectively which could result in some under reporting of the number of contacts.

Focus groups were also held with carers and providers to get their perspectives on the trial but this isn’t reported very well in the study so we don’t know if their views are consistent with the study results and if they identified any significant things that could help or stop the service working well. The authors also make some observations and mention some other studies, but it isn’t always clear if they are basing their suggestions on how access to services could be improved just on the results of this study or other things.

It is worth noting that the level of support received by families from the liaison worker was modest. Typically, it is difficult to find differences between small groups of participants unless the intervention offered is very powerful in effecting change. The authors suggest that ‘the fact that some significant differences were found in our study suggests that a relatively modest input which helps families to access services is, in fact, very powerful’ (p261). This means that a comparatively small input from a liaison worker could make a useful difference to families.

Additional papers referred to

Raghavan et al (2005) Supporting young people with learning disabilities and mental health needs from a minority community, in Making us count: identifying and

improving mental health support for young people with learning disabilities, pp63–86. Foundation for People with Learning Disabilities, London.

Economics

There was no economic modelling undertaken for this review question.

Evidence statements

For details of how the evidence is graded and on writing evidence statements, see Developing NICE guidelines: the manual.

AC1	**Access to respite care** Two studies of mixed quality (Chadwick et al 2002 ++; Douma et al 2006 +) talked about the demand and access to respite care. Chadwick et al (2002 ++), a qualitative study (n=102) reported that families that wanted respite care experienced more severe behaviour problems in the child; more severe stress in themselves; and to a lesser extent, had fewer children and were more likely to speak only English. The study also found that families wanted more respite care and variety of provision. Only 30% of families receive respite care, and 66% of those who had received respite care would have liked to have received more. The more severe the child's disabilities, the greater the likelihood and amount of use. Reasons given for not receiving respite care were: • Felt they did not need it (37.3%) • No place available (34.3%) • Not known: unaware of respite services (19.4%) • Not suitable: had declined it because they didn't want to accept an overnight placement away from home (8.9%) Douma et al. (2006 +), a cross-sectional study (n=289) reported a need for respite care was only identified by 38.9% of parents and met 61.1% of the time, needs for respite care more often present in parents of youths with more severe ID and younger age.
AC2	**Service need and service delivery** Three studies of mixed quality (Chadwick et al. 2002 ++; Douma et al. 2006 +; Knapp et al. 2005 +) talked about service needs of families of families and adults with severe learning disabilities and behaviour problems. Chadwick et al. (2002 ++), a qualitative study (n=102) found that families were more likely to want and to receive respite care if their children were older (mean age =8 years 6 months), they had more children at home and their child suffered from epilepsy. Douma et al. (2006 +), a cross-sectional study (n=289) found that parents of children with moderate ID or physical problems especially needed: respite care, activities for the child and practical/material help. Chadwick et al. (2002 ++) found that families who wanted respite care had more severe behaviour problems in the child, more severe stress in themselves. The more severe the child’s disabilities, the greater the likelihood and amount of use. In Knapp et al. (2005 +), a cross-sectional study (n=930) the use of services outside residential care for adults with learning disabilities and

	behaviour that challenges reflected the degree of intellectual disability and behaviour that challenges in the population. Individuals with more severe intellectual disabilities were more likely to use services such as speech therapy, physiotherapy or hospital-based day activities. Individuals with behaviour that challenges were more likely to use day centres/social clubs, psychologists, psychiatrists and dieticians. However, Chadwick et al. (2002 ++) also found that children who received respite care were older in the group (mean age =8 years 6 months) this may indicate a lack of service provision for younger children with severe learning disabilities and behavioural problems.
AC3	**Barriers to access – knowing and navigating, barriers to black and minority ethic families** Two mixed quality studies (Chadwick et al. 2002 ++; Raghavan et al. 2009 +) talked about some of the barriers faced by minority ethnic families in accessing services. Chadwick et al. (2002 ++), a qualitative study (n=102) found that families who were unaware of respite care were also more likely to be of African origin. Families who expressed a need for respite care were more likely to speak English, this could be because people who did not speak English were not aware of such services. Raghavan et al. (2009 +), a comparison evaluation (n=30) was specifically about helping families of Pakistani and Bangladeshi origin access services using a liaison worker. The study talked about how for many families in the study it was very daunting to seek out and find appropriate help from a wide range of services and professionals, and suggested that services need to reach out to families that need help and make the first contact, rather than the other way round. Raghavan et al. (2009 +) also said that it helps if the liaison worker comes from the same minority ethnic community as the people using services because they are ‘able to communicate with families using a common language and have a good understanding of the culture norms’ (p262).
AC4	**Barriers to access – knowing and navigating** Three studies, 2 moderate (Douma et al. 2006 +; Raghavan et al. 2009 +) and 1 high quality (Chadwick et al. 2002 ++) found that not knowing where to find help was a barrier to accessing services. Chadwick et al. (2002 ++), a qualitative study (n=102) found that 19.4% of families were unaware of respite services and there was a strong association with those families unaware of respite services also having no contact with social workers. Families who were unaware of respite care their child's level of functioning was higher. Douma et al. (2006 +), a cross-sectional study (n=289) also gave not knowing where to find help as a reason for families not receiving respite care. Raghavan et al. (2009 +), a comparison evaluation (n=30) found that families can have different perceptions on what statutory services can provide and said that services and professionals need to be clearer about what is available. In Raghavan et al. (2009 +) people that got help from the liaison ‘felt better equipped in obtaining contact with appropriate services’ (p262). While the control group felt that they had not progressed much in achieving help during the trial they ‘reported continuing difficulties in gaining necessary access to services, help and support’ (p262).
AC5	**Central information source improves access** There was a small amount of moderate quality evidence from 2 studies (Douma et al. 2006 +; Raghavan et al. 2009 +) that said having a central source of information could improve access to services. Douma et al.

	(2006 +), a cross-sectional study (n=289) found that families most often needed informal support, such as a 'friendly ear' or 'information' and said that providing a central source of information would be better for families as often they didn't know where to access support. Douma et al. (2006 +) suggested that a case manager could act as a central source and help families access support. In Raghavan et al. (2009 +), a comparison evaluation (n=30) families receiving input from the liaison worker had more frequent contact (111 liaison, 40 controls) with more services (47 liaison, 17 controls) than did families not receiving this input and had more results (33 liaison, 9 controls) from such contacts.

For Guideline Committee discussion of the evidence see the Evidence to Recommendations tables in Section 3.7.

Included studies for these review questions

Chadwick O, Beecham J, Piroth N et al. (2002) Respite care for children with severe intellectual disability and their families: Who needs it? Who receives it? Child and Adolescent Mental Health 7(2), 66–72

Douma JCH, Dekker MC, Koot HM (2006) Supporting parents of youths with intellectual disabilities and psychopathology. Journal of Intellectual Disability Research 50, 570–81

Knapp M, Comas-Herrera A, Astin J et al. (2005) Intellectual disability, challenging behaviour and cost in care accommodation: What are the links? Health & Social Care in the Community 13, 297–306

Raghavan R, Newell R, Waseem F et al. (2009) A randomized controlled trial of a specialist liaison worker model for young people with intellectual disabilities with challenging behaviour and mental health needs. Journal of Applied Research in Intellectual Disabilities 22, 256–63

3.5 Joined-up working

Introduction to the review question

The purpose of this review, which comprises 3 questions, was to be able to understand which mechanisms have been shown to work best to integrate services. Our definition of a 'mechanism' was things that need to happen or be in place for services to be integrated.

There is already a lot of evidence in NICE guidance and elsewhere that says that services that are integrated work better for people and their families than services that are not. We took the starting point that integration of service is preferred to not being integrated, we take this as assuming that things that integrate services are effective. The Guideline Committee agreed that there were different aspects of integrating care.

- When services work with each other.
- When services work with the person and their families.
- When services make sure that people are involved in sharing decisions and helping to shape the services that they receive and are right for them.

Review questions

5.1. What mechanisms enable effective joined-up working between education, health and social care service providers supporting children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers?

5.2. What mechanisms enable effective joined-up working between health and, social care providers of services and with children, young people and adults with behaviour that challenges, and their families and carers?

5.3. What mechanisms enable effective shared decision-making, empowerment and coproduction of services between education, health and social care service providers of services and children, young people and adults with learning disabilities and behaviour that challenges, their families and carers?

Summary of the review protocol

Review questions that were developed in scoping phase were discussed with the Guideline Committee and formed the basis for developing the protocols for each question. Full protocols can be found in Appendix A.

Population

People with a learning disability and behaviour that challenges, parents, families or carers of people with a learning disability and behaviour that challenges. Professionals who work with people with a learning disability and behaviour that challenges.

Intervention

Community-based services, inpatient services. interventions to improve joint working.

Setting

All settings where care is delivered.

Person-focused outcomes

Child development outcomes; continuity of care; families and carers stress and resilience; frequency, severity and duration of behaviour that challenges; health and social care related quality of life; inclusion in community life; service user involvement in planning, delivery and monitoring of services; service user, family and carer satisfaction.

Service-focused outcomes

Availability, access and uptake of local services; equity of access; meeting complex, physical and mental health needs; geographical variation in service provision (locally, regionally and nationally); level and type of support from care workers and carers; positive behaviour support; timely discharge; out of area placements; use of inpatient services.

Phenomena of interest (for views and experiences studies)

Barriers and facilitators to access to services; experiences of stress and resilience; preferences and values; involvement in the planning, delivery and monitoring of services; inclusion in community life; independence.

Study designs

Single-case evaluations, process evaluations, mixed methods studies, views and experiences studies.

Many of the studies we included had also helped us to answer some of the other research questions and could be used to help answer more than 1 question in this review. For this review, we were only interested in those elements of the study that talk about mechanisms to help services be integrated.

See Appendix A for full protocols.

How the literature was searched

A search strategy for all of the review questions combined was developed and the questions were translated into a framework of 5 concepts of: a) population (people with a learning disability and behaviour that challenges), and b) service provision (including models of services and service capacity) or c) risk management or safeguarding or d) integrated services or e) access to services. These reflected the question areas: types of service provision, service capacity, service delivery and integration of services. The search strategy was run between December 2015 and January 2016 and update searches were conducted between February and March 2017. See Appendix A for full details of the search.

How studies were selected

Results from the searches were stored in EPPI-reviewer 4 a software program designed for information management of systematic reviews. The titles and abstracts of these results were screened against inclusion criteria that was developed from the scope. Two reviewers looked at the same studies titles and abstracts independently of each other and compared their results to make sure that the inclusion criteria was understood and applied in the same way by both reviewers.

Studies that were found to meet the initial inclusion criteria were assigned to the relevant review question and the full text was retrieved for a second screening and considered against the criteria in the review question protocol.

The review team found 43 studies relevant to this set of review questions based on the title and abstract. After screening against the full text we retained a total of 13 studies. Eleven studies related to how services integrate with each other, 9 studies related to how services integrate with people who use services and their families and 5 studies related to what helps with shared decision-making and co-production of services.

Overall the study quality for this review is mixed with 9 low quality studies and 4 moderate quality studies.

See Appendix B for full critical appraisal and findings tables.

Narrative summary of the evidence

Below are the narrative summaries of included studies, including economic and cost-effectiveness studies where identified.

Ayres M, Ashok R. (2009) Supporting people with complex mental health needs to get a life! The role of the supported living outreach team

Review question(s): 3.1, 5.1, 5.2

See narrative summary in section 3.3.

Bartle J, Crossland T, Hewitt O (2016) 'Planning Live': using a person-centred intervention to reduce admissions to and length of stay in learning disability inpatient facilities

Review question(s): 5.3

Organisations the authors were involved with:

1. Learning Disability Services, Berkshire Healthcare NHS Foundation Trust

Type of study: Views and experiences of people who used the service, and post-test evaluation

Country: UK

Population: People with a learning disability receiving treatment for challenging behaviour or mental health difficulties in hospitals

Quality score: -

Type of service: A person-centred planning service to reduce admissions to and length of stay in learning disability inpatient facilities

Study aim

This study aimed to answer 3 research questions:

1. Does a 'Planning Live' meeting reduce the number of inpatient admissions to the service?

2. Does a ‘Planning Live’ meeting reduce the length of inpatient admissions?

3. Is a ‘Planning Live’ meeting experienced as helpful by those who attend?

Findings

The study found a significant differences between the before and after groups for length of stay in hospital, but there was a significant increase in the numbers of people who were admitted to inpatient.

Families and professionals said that they found the meetings helpful.

Analysis of the interviews identified 4 themes:

Working together

‘… Several people from various disciplines shared ideas, experiences and a holistic approach was valuable’.(p281)

Family Involvement

‘Being about to get everybody involved in supporting the person together, especially family.’ (p281)

Families also said that it helped to have information about the meetings in advance so that they could be properly prepared and know what to expect.

A positive approach

A theme of positive approach was identified, people appreciated a more holistic way of seeing the person, and focusing on what the person can do.

‘Liked to focus being on what the person can do, positive attributes and building on these.’(p282)

‘Facilitation focussed on what can be done rather than what was not done; avoided a negative focus on what should have or could have been done in previous placements.’ (p282)

People found it helpful to have a perspective of someone ‘outside’ of the system.

‘Input from professionals who had known client historically … gaining an independent view.’ (p282)

Conducting the meeting

This theme was about the practical aspects of holding the meetings. One of the points raised that it wasn’t always possible to have the person themselves as part of the meeting, though it was acknowledged that this was often because the person was unwell.

‘It was a shame the person was unable to attend/ contribute (although this would have been very difficult at the time).’(p282)

Considerations

The authors compare what happened to people who were referred to the service to people who were referred for in patient admission before the service was put in place. The authors point out that since 2012 the Department of Health said that people with a learning disability can require specialist support, and this should be provided into the person’s home. The new service was put in place between 2013–15, and compared to a group who were referred between 2011–13

Differences between the before and after groups could possibly be explained by a general trend to avoiding in patient admission. Without a comparison group it is difficult to say for certain that the differences between the before and after group could only be the due to the effects of this new service.

However, the study found an increase in admissions overall compared to the before group. This maybe because of local factors effecting community services and a knock on effect for demand for inpatient admission in this particular area, at that particular time but authors also point out that similar services that aim to reduce inpatient admission by person-centred planning, or providing specialist services in the person home instead of in hospital have had similar mixed results.

The feedback was generally positive, but it was not clear from the study who was speaking: whether it was a professional’s view or a family member’s view, which may be important to know whether the services was helpful for families.

Buxton L, Pidduck D, Marston G, Perry D (2004) Development of a multidisciplinary care pathway for a specialist learning disability inpatient treatment and assessment unit

Review question(s): 2.2, 3.1, 5.1

See narrative summary in section 3.2.

Carnaby S, Roberts B, Lang J, Nielsen P (2011) A flexible response: person-centred support and social inclusion for people with learning disabilities and challenging behaviour

Review question(s): 5.1, 5.2, 5.3

Organisations the authors were involved with:
1. Westminster Learning Disability Partnership

Type of study: Process evaluation

Country: UK

Population: People learning disabilities and behaviour that challenges who find it difficult to tolerate group situations or activities, and so might be at risk of their placement breaking down, or their current care package not working for them any more

Type of service: Day opportunities and supported lifestyle service

Quality score: +

Study aim

The authors describes a new interagency model of service provision that keeps social inclusion as the main aim when developing person-centred support.

Findings

What needs to happen for the service to work well?

Joined-up working between services.

Linking health and social care

The flexible response service (FRS) model provides direct support hours on a weekly basis from assistant psychologists and behaviour specialists, so that clinicians are working closely with support workers.

The junior clinical staff work in a more direct way that includes both a direct support role and clinical and service development. They provide a maximum of 15 hours direct support to people who use the service during their working week, usually but not exclusively as part of 2:1 or 1:1 support offered to a particular individual.

Staff skills

The FRS has developed a training programme that all staff have to take. this includes writing and evaluation of positive behaviour support plans, proactive low-arousal approaches and de-escalation, understanding autistic spectrum disorder, communication (and specifically a qualification in Makaton), sensory integration, risk assessment, capacity, deprivation of liberty, safeguarding and skills teaching.

Joined-up working with the person and their family

The ‘Circle of Support’ is a meeting where the person and people who are important in their social network are involved in looking at the risk assessments and achievements as much as possible, at least monthly.

Shared decision-making, empowerment and coproduction of services

This service looks at the person’s preferences and needs and what this means to create an individualised support package instead of looking only at what is available at the time.

Tailored to the person

They look at day services that are much shorter, more focused, because people can find whole-day activities too difficult to manage. The new service is about the person’s preferred activities and ability to tolerate and process sensory stimuli. Because of this, a 3- to 4-hour session is usually the maximum and initially includes 3 or 4 such sessions each week.

Assessment

People who are new to the service are first offered an assessment sessions in so called ‘safe spaces’. These are rooms in buildings locally that are for getting to know people so they can be relaxed, and also to find out what things might make people feel unsettled. Once people are more comfortable, the day sessions are moved from the ‘safe spaces’ into community-based activities.

Considerations

The study is relevant to us because the population includes people with learning disabilities and behaviour that challenges who may be at risk of being excluded from services and activities to support their daily life.

The study is a process evaluation. It looks at how a service was set up and what they did. It is not able to tell us how well the service did over time, if they carried on or if it was a better arrangement than another. The study said that there were evaluations of the service but we were not able to find these when we looked for them and they were not referenced in the paper. However, this service was designed around what services are supposed to do, based on policy and guidance.

Challenging Behaviour Foundation (2015) Paving the way: how to develop effective local services for children with learning disabilities whose behaviours challenge

Review question(s): 3.1, 5.1

See narrative summary in section 3.3.

Devapriam J, Alexander R, Gumber R, Pither J, Gangadharan S (2014) Impact of care pathway-based approach on outcomes in a specialist intellectual disability inpatient unit

Review question(s): 2.2, 3.1, 5.1, 5.2

See narrative summary in section 3.2.

Stenfert Kroese BS, Rose JL (2011) Mental Health services for adults with learning disabilities

Review question(s): 3.3, 5.1, 5.2, 5.3

See narrative summary in section 3.3.

McKenzie K, Paterson M. (2010) Evaluating an assertive outreach team for supporting clients who present behaviour that challenges

Review question(s): 3.1, 5.1, 5.2

See narrative summary in section 3.3.

National Audit Office (2017) Local support for people with a learning disability

Review question(s): 2.1, 5.2

See narrative summary in section 3.2.

Richings C, Cook R, Ashok R (2011) Service evaluation of an integrated assessment and treatment service for people with intellectual disability with behavioural and mental health problems

Review question(s): 5.1

Organisations the authors were involved with:

1. Aneurin Bevan Health Board, Torfaen, UK

2. Birmingham Learning Disability Services, UK

3. Brooklands Hospital, Birmingham, UK

Type of study: Single group, before-and-after evaluation

Country: Wales

Population: People with an intellectual disability and additional mental health and behavioural problems

Type of service: A service integrating inpatient beds, day assessment, outreach and the local community learning disability teams

Quality score: -

Study aim

This study looked at how an inpatient ward for people with an intellectual disability and additional mental health and behavioural problems was developed into a more flexible service integrating inpatient beds, day assessment, outreach and the local community learning disability teams. They looked at how the service was used in the first 2 years.

Findings

What needs to happen for the service to work well?

Joined-up working between services

The Birmingham Community Assessment and Treatment Service (BCATS) consists of 3 components:

assertive outreach,

day assessment places,

inpatient beds.

The right referral: BCATS staff may attend a community learning disability team meeting before a referral is made. Once is a referral is made it is discussed in a multidisciplinary referral meeting including the clinical leads from the community team.

Staying connected: if a person needs an inpatient bed and there isn't a bed available locally, and there needs to be a bed found somewhere else, the BCATS team is in charge of in commissioning that bed, and stays involved in the person's care management so that they can return them to the BCATS service as soon as a bed becomes available (locally).

Commitment to improvement: each service that was involved with the person agreed on improving response times along the BCATS pathway.

Considerations

This study is relevant to us because it is looking at a different way of delivering services in a more integrated way. It is limited in what it can tell us about how effective it was because it was only comparing service use back to a time when it was a very different kind of service so is not really comparable. It also looked at service use over a fairly short period of time, people can be very enthusiastic about a new way of doing things to begin with we need to see if that enthusiasm can be sustained over time to know if the service is a good idea in the long run.

However, they do look at what needed to happen to make a service like this work. It only looked at how the services might work better together, but not how services might work better with families, or encourage involvement of the person and their families in the co-production of their services. It would have been good if people who used services had some input in the beginning to say what kinds of services that wanted and whether this change in service models was preferred over the old way or if they would measure success of a service in a different way than just take-up and changes in behaviour. These results need to be considered alongside other studies about integration of services.

Sergeant EV, Brown G (2004) Housing people with complex needs: Finding an alternative to traditional service models

Review question(s): 5.1, 5.2, 5.3

Organisations the authors were involved with:

1. Aberdeen City Council

Type of study: Process evaluation – this describes how a service was set up and what it did

Country: Scotland

Population: People with challenging behaviour

Type of service: Small-scale sheltered housing and assistive technology

Quality score: -

Study aim

The aim of the research was to look at alternatives to the traditional models of supported housing to meet more complex and challenging needs. Key to this was the housing and support model.

Findings

What needs to happen for the service to work well?

Joined-up working between services

Individual assessment and planning are important to making this new model of housing and support work.

External agencies can provide expertise and guidance which will help ensure a more effective solution to individual needs. In this case the authors sought advice from experts in learning disability, autism and housing for advice on housing people with complex needs.[15]

Thinking and working across professional boundaries would need to include statutory and voluntary agencies.

Joined-up working with the person and their family

The living environment needed to be responsive to the individual and what they need. It needs to offer independence, privacy and safety, and that support had to be flexible, responsive and provided by skilled staff who were consistent and had the right training to meet different needs.

Shared decision-making, empowerment and co-production of services

The first point of the design process is the individual assessment of need by the care manager. They should assess and bring together information, with the multidisciplinary team, parents, carers and the person who will use the service. The

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[15] Housing providers, Lancaster and Robert Gordon Universities, National Autistic Society and the Scottish Society for Autism.

assessment should say what service there should be, not what services are available.

Considerations

This study was done some time ago. The authors say that ‘at the time of the study, there were substantial group home resources, some isolated single tenancies, specialist nursing homes and residential provision’ (p30). This type of solution might not be so easy to do in areas where there is high housing demand and less resources. The way that housing benefit is paid to registered social landlords has also changed over time and Scotland may have different rules than Britain.

Toogood S, Saville M, McLennan K, McWade P, Morgan G, Welch C, Nicholson M (2015) Providing positive behavioural support services: specialist challenging behaviour support teams

Review question(s): 3.1, 5.2, 5.3

See narrative summary in section 3.3.

Watson J M, McDonnell V, Bhaumik S (2005) Valuing people: evaluating referral systems. A study of a multidisciplinary single point of referral system to dedicate adult learning disability health services in Leicester, UK

Review question(s): 5.1

Organisations the authors were involved with:
1. Associate specialist, learning disability service, Leicestershire Partnership NHS trust and research associate, University of Leicester

2. Service development manager (previously practice development nurse facilitating the single point of referral pilot project), University of Leicester

3. Consultant psychiatrist, learning disability service

4. Leicestershire Partnership NHS Trust and honorary senior lecturer, University of Leicester

Type of study: single group before-and-after evaluation

Country: UK

Population: Adults with learning disabilities, a third of referrals were people with learning disabilities and also behaviour that challenges

Type of service: A single point of referral service

Quality score: -

Study aim

The overall aim of the study was to assess the impact of establishing a multidisciplinary single point of referral system (SPR) in Eastern Leicester PCT. The objectives were to make the following comparisons before and after the new system was introduced: the number and demographic characteristics of individuals referred; the sources of referrals; the reasons for referrals; the appropriateness of referrals; the average number of professions involved in the care of each patient; the mean waiting time between referral and assessment; and the perception of communication between professionals (p158).

Findings

What needs to happen for the service to work well?

Joined-up working between services

Shared language: the new single point of referral used a common referral criteria and a streamlined information system.

Awareness of the new system: a new referral form and an information leaflet about the SPR system were developed and copies distributed to social workers, day centre managers, GPs and colleges of further education.

Multiagency working: a representative from each profession attended weekly SPR team meetings, where referrals were assessed and action plans agreed. A social worker attended these meetings about once a month.

Considerations

This was only 1 group that looked at what the service was like after a service was put in place compared to how it was before. Evaluations that only have 1 group are often not very reliable because we don’t know if any good effect they saw was due only to this new service or some other reason, or if it is better than the usual way for everyone or just better than the way they did things before. It only looks at what happens a short time after the service was put in place (6 months) compared to a short time before (3 months), so It doesn’t tell us if any of the improvements they saw will carry on into the future as people can be enthusiastic to begin with when there is a new way of doing things. But it does have interesting information on how they set the new service up and what they said needed to be in place for this new way of doing things was to work. For this reason the findings should be treated with caution and the lessons they learned considered alongside other studies.

Economics

No economic analysis or modelling was undertaken for this review question.

Expert testimony

The need for expert testimony

We wanted to know if there was any early learning from the Transforming Care programme about what services can do to make sure that they work well with other services, the person with learning disabilities and behaviour that challenges, and their families and carers, and enable effective shared decision-making, empowerment and co-production of services between education, health and social care service providers and children, young people and adults with learning disabilities and behaviour that challenges, their families and carers.

Testimony

The full testimony from the expert witnesses from Transforming Care can be found in Appendix D. A brief summary of their testimony is given below.

Expert testimony was provided by a clinical lead and representative from an organisation that supports people who use services on the Transforming Care board. Their testimony highlighted that there are a number of factors that can help services work well with other services. These include: clear vision; shared vision and ambitions; clarity on roles and responsibilities; bringing everybody together from the start; co-production at every level; local leadership; letting people know what you need now and what is coming up; thinking broadly regarding involvement; transforming care plans (TCPs) as a platform; communication; glossary of terms; and information about how to get involved.

When it comes to working well with the person with learning disabilities and behaviour that challenges, and their families and carers, the expert witnesses suggested that it is important to provide good advocacy and good information about options available. They also said that it important to engage with people at the earliest point and to be proactive. Finally, they suggested that true co-production means involving everyone.

Their testimony also highlighted that to enable effective shared decision-making, empowerment and co-production, the following are considered key:

- empowering people – as citizens – to understand and be involved in processes, early on
- using personal health budgets, education health and care plans or annual health checks as helpful levers to enable change
- quality assurance at all levels, ‘measure what you value not value what you measure’.

Evidence statements

For details of how the evidence is graded and on writing evidence statements, see Developing NICE guidelines: the manual.

INT1	**Regular opportunities for professionals from different teams to meet** There were 4 UK studies of low quality overall (Challenging Behaviour Foundation 2015 −; McKenzie and Paterson 2010 +; Richings et al. 2011 −; Watson et al. 2005 −). These reported that having services or meetings in the same place (‘co-located’) helped different services work together. In Watson et al. (2005 −) a single group before-and-after evaluation (n=190) a representative from each profession attended weekly ‘single point of referral’ system team meetings. This was where referrals were assessed and action plans agreed. A social worker attended these meetings about once a month. In another study (McKenzie and Paterson 2010 +) a process evaluation (n=24), the assertive outreach team (AOT) was co-located with the community learning disability team (CLDT) which was found to help the services work better together. The Challenging

	Behaviour Foundation (2015 -) process evaluation of (n=5 services) found that it was helpful if people from different organisations met monthly. Some people were from local organisations and some from national ones, like the NHS. In the Richings et al. a single group, before-and-after evaluation (2011 -) (n=102), the Birmingham Community Assessment and Treatment Service (BCATS) found that it helped to have the team attend community learning disability team meetings before a referral is made. Once a referral is made, it is discussed in a referral meeting which involves different professionals (a 'multidisciplinary' meeting) and includes the clinical leads from the community team.
INT2	**Drawing in expertise** Five UK studies of mixed quality (Ayres and Roy 2009 −; Bartle et al. 2016 −; Stenfert Kroese and Rose 2011 +; Sergeant and Brown 2004 −; Watson et al. 2005 −) found being able to draw in expertise from outside their own organisation can help different agencies work better. In Watson et al. (2005 −) a single group before-and-after evaluation (n=190), a representative from each profession attended weekly single point of referral system team meetings. This was where referrals were assessed and action plans agreed. In Sergeant and Brown (2004 −), a process evaluation (n=55) the authors asked the advice of experts in learning disability, autism and housing. They found that external agencies can provide expertise and guidance which will help ensure a more effective solution to individual needs. Stenfert Kroese and Rose (2011 +) a qualitative study (n=54) found that staff in mental health services who care for adults with learning disabilities and mental health problems need to be able to communicate easily with different services. In Ayres and Roy (2009 −) a process evaluation (n=26), the supported living outreach team have developed partnership arrangements with independent sector providers and the local community team. This is so that they can manage a crisis in a person's home with familiar, dedicated staff to prevent admission to hospital. Additionally, Bartle et al. (2016 −), a mixed methods study (n=102) about using planning meetings to help reduce admissions to and length of stay in inpatient facilities, found that 1 of the main reasons why families and professionals found the meeting helpful was because several people from different disciplines were involved and shared ideas and experiences and this provided an opportunity to share information with others in the system.
INT3	**Working with communities** One process evaluation (n=26) of low quality (Ayres and Roy 2009 −) talked about the importance of understanding and responding to any concerns in local neighbourhoods. They found this helps build relationships with neighbours, local councillors, and police and antisocial behaviour teams. They found that it helped to have additional funding for 'a property damages fund'. This is to persuade private landlords and housing associations not to exclude people who may have had a history of property damage.
INT4	**Linking health and social care** There were 5 studies of low overall quality that found making links between different sectors helps services work together in a 'joined up' way (Buxton et al. 2004 −; Carnaby et al. 2011 +; Challenging Behaviour Foundation 2015 −; Devapriam et al. 2014 +; Stenfert Kroese and Rose 2011 +). Buxton et al. (2004 −), a process evaluation (n=not specified) reported that

	the wider health and social care team should be involved in the process of assessment and treatment. The Carnaby et al. (2011 +) process evaluation (n=not specified) said it helps if assistant psychologists and behaviour specialists work together, so clinicians work more closely with support workers. The Challenging Behaviour Foundation (2015 −) process evaluation of (n=5 services) found that it was helpful if people from different organisations met monthly. Some were from local organisations and some from national ones, like the NHS. One study, Devapriam et al. (2014 +), an evaluation of a single group (n=24), found that the inpatient care pathway works well when people from different organisations are involved, such as community teams, local authorities and clinical commissioning groups. This helps to speed up the discharge process. In the Stenfert Kroese and Rose (2011 +) a qualitative study (n=54), staff in mental health services said it helps to be able to meet community learning disability teams so they can learn from each other. They also said that it helps if the health team and the mental health team can work together. In particular, they said it is important for people to work together to make sure that when regular health checks are done, healthcare staff know how to include checking people's mental health. This is because if you can spot when someone is sad, frightened, angry or confused a lot of the time, you can help them sooner.
INT5	**Roles and responsibilities** Four UK studies of low overall quality reported that it helps to be clear about the roles and responsibilities of different service so that they can work better together (Ayres and Roy 2009 −; Challenging Behaviour Foundation 2015 −; Stenfert Kroese and Rose 2011 +; Richings et al. 2011 −). In the Ayres and Roy 2009 −), process evaluation (n=26), the supported living outreach team had written documents to support the care provider. These documents made clear where roles and responsibilities overlap in respect of providing supported living services to clients. They did this by being clear about: the roles and responsibilities of the team; the role of the community learning disability team; the role and responsibilities of the care provider organisations; the process for deciding how much money is available, and reviewing this; the process for setting people up in their own homes; details about how support will be monitored; and plans to help people in a crisis. The Challenging Behaviour Foundation study (2015 −) process evaluation of (n=5 services) found that having a clear framework helps make individual professionals accountable to their clients. This framework should include policies and guidance relevant to health and social care, as well as information about what should be done when, and who is responsible for doing it. McKenzie and Paterson (2010 +), a process evaluation (n=24), found that it helped to be clear about what the assertive outreach team is responsible for doing, and who will do what. This helps make sure communication with the wider learning disability team is good. Stenfert Kroese and Rose (2011 +), a qualitative study (n=54), found that staff need to be clear about what they are trying to achieve when working with other services. They also said that services must work together, and not avoid taking responsibility). Their study says it is not enough for a service to simply say that a person is not suitable to be helped by them. They should work with other services first, before just excluding them. In Richings et al. (2011 −) a single group, before-and-after evaluation (n=102), the multidisciplinary care pathway (BCATS) consisted of assertive outreach, day assessment places and inpatient beds. The study found that

	that multidisciplinary working worked best when each service that was involved with the person agreed on improving response times along the BCATS pathway.
INT6	**Developing new services** There were 2 UK studies of low quality which reported that involving and promoting new services helped different services work together (Buxton et al. 2004 −; Watson et al. 2005 −). Buxton et al. (2004 −), a process evaluation (n=not specified) found that, when developing a new pathway, it is helpful to involve everyone who will be needed to deliver care and support from the start. This is so they understand the purpose of the pathway, get involved in the work to put it in place, and carry on using it. Watson et al. (2005 −), a single group before-and-after evaluation (n=190), reported that to raise awareness of the new multidisciplinary single point of referral (SPR) system an information leaflet was developed and sent out to professionals who would use the new referral system. This aimed to make sure people knew about the referral system. They sent it to social workers, day centre managers, general practitioners and colleges of further education.
INT7	**Single coordinator** There is a small amount of mixed quality evidence (Devapriam et al. 2014 +; Stenfert Kroese and Rose 2011 +, NAO 2017 −) that having 1 person in place can help services work better with families. This person can help coordinate services and be a single point of contact for the person and their family. Devapriam et al. (2014 +), an evaluation of a single group (n=24) found that having 1 person coordinate a care pathway approach is helpful. This person was a band 6 nurse working full-time. We do not know from the evidence what it was about this particular person that made the coordinator role work well. The other study (Stenfert Kroese and Rose 2011 +), qualitative study (n=54) found that when providing services for adults with learning disabilities and mental health problems, having 1 ‘professional person’ in place who can help coordinate services and be a single point of contact for the person and their family is helpful. Additionally, evidence from the NAO (2017 −) mixed-methods – audit which looks at the progress the government has made with its Transforming Care programme to provide community services and reduce mental health hospital beds for people with a learning disability, supports this statement. In NAO (2017 −) it was the view of some families that ‘without a single point of contact to effect change and coordinate resources, families found the process of discharge from mental health hospitals to be incomprehensible and emotionally draining’ (p35).
INT8	**A team around the person** There was low quality evidence (Ayres and Roy 2009 −; Challenging Behaviour Foundation 2015 −; Bartle et al. 2016 −; Sergeant and Brown 2004 −) which said that building a service around the person helps to make sure that services work better with the person and their family. Ayres and Roy (2009 −), a process evaluation (n=26) found that it helped to be able to increase the numbers of staff around a person, if that person had more complex needs. This helped because it meant that more staff could get to know the person. When more staff know the person, it means that replacements of staff can be done at short notice and with the smallest amount of disruption to the person’s support. They also said that a

	keyworker system works best when it works more like an equal partnership than a typical ‘staff–service user’ relationship. Sergeant and Brown (2004 −), a process evaluation (n=55) found that the living environment needed to be responsive to the individual and what they need. They also found that the support to the person needs to be flexible, responsive and provided by skilled staff. The staff should not change too much and they also need to have had the right training to meet different people’s needs. Early findings from process evaluation of (n=5 services) by the Challenging Behaviour Foundation (2015 −) found that children aged 0 to 5 can benefit from a ‘team around the child’ (TAC) package to provide the support that is right for the family. They are able to choose a keyworker from this team to coordinate the support for the child and for the family. Additionally, Bartle et al. (2016 −), a mixed methods study (n=102) about using planning meetings to help reduce admissions to and length of stay in inpatient facilities, found that having as many people as possible involved in supporting the person attend the meetings helped create a more positive approach and holistic way of seeing the person.
INT9	**Regular reviews** Three mixed quality studies (Carnaby et al. 2011 +; Challenging Behaviour Foundation report 2015 −; Stenfert Kroese and Rose 2011+) talked about the importance of having regular reviews (where people can discuss whether the arrangements are still working for everyone). They also talked about how important it is to involve experts by experience in reviews, and people’s wider social networks. One process evaluation (n=not specified) (Carnaby et al. 2011 +) looked at a ‘circle of support’. This was a regular meeting involving everyone who is important to the person. These people met at least monthly. They used the meeting time to look at what the services had achieved for the person and to talk about any risks. The mental health services studied by Stenfert Kroese and Rose (2011 +), a qualitative study (n=54) said it helps to have regular meetings and reviews with people using services. This is to talk about the help they are getting and make sure no one is overlooked because they are ‘borderline’ between services. Regular meetings and reviews make sure that staff have good ways of communicating and this helps them work well together. The Challenging Behaviour Foundation (2015 −) process evaluation of (n=5 services) noted that children placed out-of-area should have their progress regularly reviewed.
INT10	**Locally-based services** Two mixed quality UK studies of what people think (Challenging Behaviour Foundation 2015 −; McKenzie and Paterson 2010 +) talked about how services can support the person and their family to have a more joined-up experience of care. In the McKenzie and Paterson (2010+), process evaluation (n=24), the authors talked to staff who worked with the assertive outreach team. Staff said that people’s care is ‘joined up’ when the service is based locally, when it is easy and fair for people to get to use it. The Challenging Behaviour Foundation (2015 −) process evaluation of (n=5 services) said it is important to develop a local approach to managing crisis so that children don’t have to move. Where possible, they should stay near where they currently live and ideally in their family home and community settings long term. They found that people who used the short breaks service were more likely to stay in the community, and that this meant people and their families had a better quality of life.

INT11	**Personal qualities of staff** One moderate quality study talked about the importance of staff supporting people having the right personal qualities. Stenfert Kroese and Rose (2011+), a qualitative study (n=54) talked to professionals and people using services for adults with learning disabilities and mental health problems. They asked them about the personal qualities needed by people working in this field. They said that families and support staff have needs too and they must be listened to, because if they are unhappy, the person using the service will also be made unhappy. Staff need to be sensitive to understand when problems should be discussed in private and when they should be discussed with other people. Families and unpaid carers sometimes want to talk about things they are going through without others there. Other times, it can be useful for them to talk about problems together with family or support workers.
INT12	**Enable access to support at the right time** There were 3 moderate quality studies (Challenging Behaviour Foundation 2015 −; Stenfert Kroese and Rose 2011+; Toogood et al. 2015 −). The study by (Stenfert Kroese and Rose 2011 +), qualitative study (n=54) talked about the importance of giving the right support at the right time. When staff undertake regular health checks they should also think about the person's mental health. This is so that if people are sad, frightened, angry or confused a lot of the time, they can be helped as soon as possible. Helping people at the right time, means helping people as early as possible, so that their problems don't get worse. The study said that all mental health services must be open to people with learning disabilities, including memory clinics and talking therapies. Toogood et al. (2015 −), a process evaluation (n=not specified) talked to positive behavioural support services (PBSS) staff. These staff worked with professionals and staff in mainstream intellectual disability services to support people and their families. They found that positive behaviour support staff offer help in a way that is person-centred. They found that this can increase parents' confidence when responding to behaviour that challenges. The Challenging Behaviour Foundation (2015 −) process evaluation of (n=5 services) found that it helps if families can get intensive, child-focused, one-to-one support to assess their child's needs and provide access to the right interventions. They said this can prevent out of area placements.
INT13	**Care pathway – prevent delays in getting help from services** Two UK evaluation studies of mixed quality (Toogood et al. 2015 −; Devapriam et al. 2014 +) reported that care pathways can help prevent delays in people getting the help they need, and make sure they get the right kinds of support. Toogood et al (2015−), a process evaluation (n=not specified) found that care pathways are part of specialist challenging behaviour support services because they help prevent delays in people getting the help they need, and to make sure they get the right kinds of support. In Devapriam et al. (2014 +), an evaluation of a single group (n=24), the care pathway included the referral, assessment, treatment and discharge from an inpatient unit. A person coordinating care was also part of the pathway, making sure the person needing support moves from 1 service or setting to another smoothly. They found that having the care pathway in place resulted in better outcomes in people, including less time in hospital and assessments and treatments which happened at the right time for the person.

INT14	**Having a choice** Two moderate quality studies (Carnaby et al. 2011 +; Stenfert Kroese and Rose 2011 +) talked about the importance of giving people choices. In Carnaby et al. (2011 +) a process evaluation (n=not specified), the service looks at the person’s preferences – what the person liked and wanted, didn’t like and didn’t want – as well as what they need. This was so they can put together a truly individualised support package. The new day services are much shorter compared to whole-day services and are for people who find whole-day activities too difficult to manage and so can be excluded from day activities altogether. The services are organised to help the person do what they want to do, and what they are able to do. Stenfert Kroese and Rose (2011 +), a qualitative study (n=54) found that people who use services should help with choosing workers. Workers need to have good ‘people skills’ and should be people who are really interested in doing the job.
INT15	**Assessment for tailor-made services** Four studies – 3 low quality (Bartle et al. 2016 −; Sergeant and Brown 2004 −; Toogood et al. 2015 −) and 1 moderate quality (Carnaby et al. 2011 +) – talked about how to assess people in a way that makes it possible to design services especially for them. They said it is important to find out what people prefer as well as what they need. This information should then be used to build services around the person. Two studies (Carnaby et al. 2011 +; Sergeant and Brown 2004 −) said that assessment should find out the person’s preferences as well as their needs. They found that assessment should use this information to say what service should be in place, rather than expecting the person to just fit in with what services are available. The process evaluation (n=55) by Sergeant and Brown (2004 −) was about finding suitable supported housing for people with complex and challenging needs. They reported that the design process starts with an individual assessment of need by the care manager. The study found that the assessment should bring together lots of different information. This could be from the multidisciplinary team, parents, carers and the person who will use the service. The assessment should say what service should be put in place to support the person. In Carnaby et al. (2011 +), a process evaluation (n=not specified), the assessment for people who are new to the person-centred day opportunities and supported lifestyle service are first offered an assessment session in so called ‘safe spaces’. These ‘safe spaces’ are rooms in local buildings that are used to get to know people. The important things is that these spaces help people to feel relaxed and comfortable talking about what they need. People are also asked about what things might make them feel unsettled, before moving their day activities to a community setting. In the Toogood et al. (2015 -) process evaluation (n=not specified), specialist challenging behaviour support staff worked with the person and people important to them to create packages of support. This means the service is designed especially for that person, not based on what is already there. Sometimes this means building on services that are already there. Sometimes it means putting a new service in place. Professionals partner the person and their family to bring insight, knowledge, expertise and resources. The exact nature of the work varies between individuals and aims to work towards whatever a particular person needs.

	Additionally, Bartle et al. (2016 −), a mixed methods study (n=102) about using planning meetings to help reduce admissions to and length of stay in inpatient facilities, found that having planning meetings that involved everyone supporting the person, including the family helped to create a more positive approach and focus on what the person can do and to build on this.
TC01	**PHBs & EHC plans as helpful levers to implement a good service model** This evidence statement is based on Expert witness testimony of current good practice seen in Transforming pilot area programmes. (comprised of a representative from the Transforming Care Partnership Board and who also works for a UK charity which supports people with sight loss and a lead clinical practitioner on the Transforming Care board). PHBs & EHC plans and Annual health checks can be helpful levers for change. It is helpful to inform people as to why it is necessary to see things change but also helpful to know what levers (the things people must do if they want to get paid for example) are available to make change happen

For Guideline Committee discussion of the evidence see the Evidence to Recommendations tables in Section 3.7.

Included studies for these review questions

Ayres M, Roy A (2009) Supporting people with complex mental health needs to get a life! The role of the supported living outreach team. Tizard Learning Disability Review 14(1), 29–39

Bartle J, Crossland T, Hewitt O (2016) ‘Planning Live’: using a person-centred intervention to reduce admissions to and length of stay in learning disability inpatient facilities. British Journal of Learning Disabilities 44, 277–83

Buxton L, Pidduck D, Marston G et al. (2004) Development of a multidisciplinary care pathway for a specialist learning disability inpatient treatment and assessment unit. Journal of Integrated Care Pathways 8, 119–26

Carnaby S, Roberts B, Lang J et al. (2011) A flexible response: person-centred support and social inclusion for people with learning disabilities and challenging behaviour. British Journal of Learning Disabilities 39, 39–45

Challenging Behaviour Foundation (2015) Paving the way: how to develop effective local services for children with learning disabilities whose behaviours challenge. Chatham: Challenging Behaviour Foundation

Devapriam J, Alexander R, Gumber R et al. (2014) Impact of care pathway-based approach on outcomes in a specialist intellectual disability inpatient unit. Journal of Intellectual Disabilities 18(3), 211–20

McKenzie K, Paterson M (2010) Evaluating an assertive outreach team for supporting clients who present behaviour that challenges. British Journal of Learning Disabilities 38, 319–27

National Audit Office (2017) Local support for people with a learning disability. London: NAO

Richings C, Cook R, Roy A (2011). Service evaluation of an integrated assessment and treatment service for people with intellectual disability with behavioural and mental health problems. Journal of Intellectual Disabilities 15, 7–19

Sergeant EV, Brown G (2004) Housing people with complex needs: Finding an alternative to traditional service models. Housing and Care & Support 7, 25–30

Stenfert Kroese B, Rose JL (2011) Mental health services for adults with learning disabilities. London: The Judith Trust

Toogood S, Saville M, McLennan K et al. (2015) Providing positive behavioural support services: specialist challenging behaviour support teams. International Journal of Positive Behavioural Support 5, 6–15

Watson JM, McDonnell V, Bhaumik S (2005) Valuing People: Evaluating Referral Systems. A Study of a Multidisciplinary Single Point of Referral System to Dedicated Adult Learning Disability Health Services in Leicester, UK. The British Journal of Development Disabilities 51(101), 155-70

3.6 Additional review question: assistive technology to support independent living

Introduction to the review question

The Guideline Committee wanted to know if assistive technology helps people with learning disabilities and behaviour that challenges live in their own home independently. We did not find any studies that answered this question directly for this population in our data set, but the Guideline Committee agreed that studies about assistive technology that support independent living for all people with learning disabilities would be able to help answer that question. We conducted an additional search about assistive technology for people with learning disabilities.

Review questions

6.1 What is the effectiveness of different types of assistive technology to support independent living for adults with learning disabilities?

6.2. What is the cost-effectiveness of different types of assistive technology to support independent living for adults with learning disabilities?

6.3. What are the views and experiences of adults with learning disabilities who use different types of assistive technology to support independent living?

Summary of the review protocol

Review questions that were developed in scoping phase were discussed with the Guideline Committee and formed the basis for developing the protocols for each question. Due to the lack of high quality evidence on assistive technology that was specific for our population, the inclusion criteria was expanded to include all people with learning disabilities Full protocols can be found in Appendix A.

Population

Adults with a learning disability, their parents, families or carers of people with a learning disability. Professionals who work with adults with a learning disability.

Intervention

Assistive technology to support independent living, including home adaptations, bed sensors, alarms, remote monitoring, apps.

Setting

People's homes where people live independently or with support.

Person-focused outcomes

Health and social care related quality of life; inclusion in community life; service user involvement in planning, delivery and monitoring of services; service user, family and carer satisfaction.

System-focused outcomes

Availability, access and uptake of local services; equity of access; meeting complex, physical and mental health needs; geographical variation in service provision (locally, regionally and nationally); level and type of support from care workers and carers.

Phenomena of interest (for views and experiences studies)

Barriers and facilitators to access to services; experiences of stress and resilience; preferences and values; involvement in the planning, delivery and monitoring of services; inclusion in community life; independence.

How the literature was searched

The additional search for assistive technology to support independent living was conducted between August and September 2016, looking for literature on assistive technology and people with learning disabilities or behaviour that challenges relating to types of service provision. See Appendix A for full details of the search.

How studies were selected

The search strategy generated 337 results which were stored in EPPI-reviewer 4, a software program designed for information management of systematic reviews. The titles and abstracts of these results were screened against the following inclusion criteria:

- Exclude: duplicate.
- Exclude: Date. Published before Valuing People and the Health and Social Care Act 2001.
- Exclude population: not about adults with learning disability.
- Exclude intervention: not about assistive technology to support independent living.
- Exclude evidence type: not empirical research.

Two reviewers looked at the same studies titles and abstracts independently of each other and compared their results to make sure that the inclusion criteria were understood and applied in the same way by both reviewers.

The review team found 38 studies relevant to this review question based on the title and abstract and these were retrieved and screened against the full text and 7 met the inclusion criteria in the protocol and were included for these review questions. We found 1 systematic review of assistive technology for the home, 1 study looked at the effectiveness of assistive technology, 3 studies looked at costs and outcomes, 1 study was about the views and experiences of assistive technology and 1 study was a report without a robust study design. We found 1 high quality systematic review, but that review did not find any good quality studies nor much evidence that assistive technology helped people live independently. This could be that there are many types of assistive technology used for different things and the technology is changing all the time.

See Appendix B for full critical appraisal and findings tables.

Narrative summary of the evidence

Below are the narrative summaries of included studies, including economic and cost-effectiveness studies where identified.

Bye G, Gibson M (2009) A review of assistive technology and its impact

Organisations the authors were involved with: The Life Path Trust

Type of study: Case study

Country: UK

Population: Adults with a learning disability

Quality score:-

Type of service: The type of assistive technology varied but the main components were the use of a central control panel linked to a call centre that responds to both active and passive sensors

Study aim

This study reports on the impact of assistive technology on n=3 individuals with learning disabilities within Coventry City Council as delivered by the Life Path Trust for 2.5 years since 2007. Individuals supported by the organisation ranged in ability and support hours that were needed.

Background

This report discusses various types of assistive technology used within Coventry City Council. The main components of assistive technology were the use of a central control panel linked to a call centre that responds to both active and passive sensors. The staff at the call centre either talk to the individual in their home or alert appropriate staff or medical services. A standby team are available 24 hours a day and can be with a service user within 30 minutes. Examples of assistive technology include a personal alarm trigger, an intruder alarm, bed occupancy mat, epilepsy mat, and flood detector.

Findings

The authors provide 3 case studies of individuals with learning disabilities but none of which have challenging behaviour. The authors proceed to describe the potential benefits to the service user and potential financial savings. The authors say that the potential benefits for the individual is increased independence (for example, no longer does someone check-in every 10 minutes) and reassurance (can call for help when needed). The methods of these findings are not clearly reported – it is unclear from whom outcomes were measured.

The authors also report potential financial savings – for example, substituting waking staff support with the use of sleep-in support and alarms and alerts and reductions in the amount of waking hours support. The authors illustrate potential cost savings arising from this substitution and estimate a savings of £108,058 per year (2009 prices) in the first year of implementation, based on individuals living in 8 properties. The authors also estimated a savings of £170,747 per year for 6 individuals who moved from shared housing into flats with 2 bedrooms

Considerations

A limitation of this report is that the data collection methods and the characteristics of the participants were not described or were not clearly described. Likewise, the financial data does not come with a clear description of the underlying data (characteristics, accommodation type).

Conclusions

While these findings are promising, the report is limited by the lack of reporting methods. Findings must be treated with caution until stronger study designs are used to increase confidence in the results.

Cheshire East Council (2010) Cheshire East Council: enabling adults with a learning disability

Organisations the authors were involved with: Cheshire council

Type of study: Impact on costs evaluation

Country: UK

Population: Adults with a learning disability

Quality score:-

Type of service: Telecare

Aim and methods

Cheshire East Council reports on the use of telecare for supporting individuals with learning disabilities within its council area (n=18). The report provides background demographic information, drivers for the use of telecare and the potential uses of various technologies It estimates the costs of setting up telecare and summarises select examples of individuals using telecare and its impact (costs and outcomes) on support staff at night-time and general effects on care packages and crises.

Findings

The Council reports that the cost of implementing telecare equipment for approximately 100+ individuals was £51,000 for the year, comprised of £46,900 for staffing costs, training, and promotion, and £2,900 for set-up costs (costs reflect the 2008/09 year) (p.4). The authors report on the impact of a sub-sample of these individuals. They find that the introduction of telecare resulted in an increase in some individuals' support packages, whereas others had had no changes, and yet others had decreases in care packages. The Council does not provide a detailed description, breakdown, or explanation as to the motivations in the change in care packages.

The Council also reports that as a result of telecare some individuals moved into more independent living, for example, from supported living to living on their own. Other individuals, as a result of receiving telecare were able to avoid a move into institutional settings.

The Council also provides one case study which is directly applicable to this guideline: an individual with autism and challenging behaviour was identified to have increasing challenging behaviour when level of staffing increased. As a result, the Council decided to use assistive technology which allowed this individual to leave hospital and move into a house in the local area.

Considerations

The report by the Council uses a case study methodology with very limited description of their methods and lacks detailed reporting of sample characteristics. Furthermore, the case studies only report on changes in accommodation and care package intensities but do not report on how this affected individuals' outcomes. As a result of a lack of reporting and the absence of measuring individuals' outcomes, reliability and validity of the findings is unclear.

Conclusion

In conclusion, a more robust study design is needed to understand the impact of assistive technology on individuals' outcomes and how it affects their use of services.

Harris J (2010) The use, role and application of advanced technology in the lives of disabled people in the UK

Organisations the authors were involved with: The Interdisciplinary Disability Research Institute, School of Education, Social Work and Community Education, University of Dundee

Type of study: Qualitative study of views and experiences – focus groups and one-to-one interviews

Country: UK

Population: Assistive technology users, designers, engineers and service providers, personal assistants, adults with disabilities and families

Quality score: -

Type of service: Assistive technology

Study aim

To explore the challenges, barriers and facilitators to acceptance and acceptability of advanced technological devices designed to assist and support independent living (p429).

Findings

What worked well?

Although not yet available, people said that an independent source of advice on advanced technological products was deemed by users to be necessary to learn more about suitable assistive technologies.

One user spoke about sensible solutions to problems, and gave an example of an engineer who assessed what the problem was (that the headset was difficult to get on easily, once taken off) and fixed the headset with a bit of a fishing rod so that it worked as the person needed it to.

Good training and support was listed as 1 of the things that made the use of the technology work well.

What got in the way?

Using computers and software was sometimes frustrating, and this made people give up on them.

‘It kept coming up with “cannot open, another programme is running” so I lost interest.’

Sometimes the technology that was supposed to be useful wasn’t adapted to the needs of the person and was impossible to use. An example was given of a universal remote control that didn’t have raised buttons, so the person with a visual impairment couldn’t use it.

Another example was given of beds that are supposed to raise, but were so difficult to use in practice that people struggled to get out of bed by themselves.

The programming of words into an augmentative and alternative communication (AAC) device was up to the professional, but the person who used the device wasn’t able to programme in their own words as they liked, like swear words.

Some users said they wanted greater flexibility of devices so they were more useful for the particular person who was using them. An example given was a pager system that didn’t indicate if there had been a missed called, something taken for granted on mobile phones.

People said that they had to rely on other people to make the devices work properly and this made people feel dependant, or that they were taking advantage of family help and time.

The focus group thought of lots of different ideas for technology that isn't available yet, such as a facial expression controlled electric wheelchair, a small, light conference folder (portable loop system), an 'emotions clock' for autistic children who do not speak, a light and portable 4-wheeled walker, a cheap and useable videophone so that deaf people can sign to each other, a device that translates the spoken word into text instantly on a phone, and for cinemas to caption (subtitle) all films. Other ideas included a machine that converts speech to text without going through the medium of a palantypist or human operator, a solar powered battery for a 'talker' (communication device) (as the batteries are constantly wearing down), several devices for gardening, and a multiple-use device that could enable a wheelchair user to turn small knobs, for example heating controls or light switches, via a long pole mounting. A voice activated fully automatic car was also desired, but the current models all require some degree of hand control (p430).

People said there was little choice or flexibility offered if the technology came from the NHS, but there was much more choice if you could afford to pay for it yourself.

Considerations

There was little information in this study that is directly relevant to assistive technology to support independent living, although it might be said that all of these technologies support independence to some degree. It is not clear how relevant this study is for people with learning disabilities, as many of the opinions are from people with physical disabilities and/or sensory impairments, although the researchers made sure that people with physical, sensory or multiple impairments, learning difficulties, mental health issues and/or chronic illness could participate.

One of the barriers to using technology, people said, was the time and effort taken to learn how to use it, but we do not know what adaptations would be helpful in helping people learn how to use their assistive technology in a way that is best for them.

Martin S Kelly G, Kernohan WG, McCreight B, Nugent C (2009) Smart home technologies for health and social care support

Organisations the authors were involved with:

1. Faculty of Life and Health Sciences, University of Ulster at Jordanstown, Belfast, UK

2. Faculty of Social Sciences, University of Ulster, Belfast, UK

3. Faculty of Computing and Engineering, University of Ulster, Belfast, UK

Type of study: Cochrane systematic review – included randomised controlled trials (RCTs), quasi-experimental studies, controlled before-and-after studies (CBAs) and interrupted time series analyses (ITS)

Country: Various

Population: People with a physical disability, dementia or a learning disability, adults over the age of 18 living in their home in a community setting

Quality score: ++

Type of service: Smart home technology

Aims and methods

To systematically review the available evidence of smart home care technology in health and social care.

Findings

The authors did not find any high quality studies that met their criteria. They conclude that without high quality studies it is not possible to decide whether smart home care technology is effective or not and that there should be more high quality studies that can evaluate this.

Considerations

Although the review did not find any high quality studies (an empty review), it does tell us that there are no high quality studies that were published before the publication submission date of 2009, but there may have been studies we can look for that were published afterwards.

Perry J, Beyer S (2009) The impact on objective technology of life outcomes of assistive technology in residential services for people with learning disabilities

Organisations the authors were involved with: Centre for Learning Disabilities, Cardiff University, UK

Type of study: A single group, before-and-after evaluation

Country: Wales, UK

Population: Adults with learning disabilities – data was collected from staff who knew the people well, 30 residents in 10 of the 32 homes where the assistive technology was installed

Quality score: -

Type of service: Residential services

Study aim

The study measured people’s participation in physical wellbeing, social and community activities and inclusion of family members 1 month before the assistive technology was installed and 9 months afterwards.

Findings

The study couldn’t find a clear difference in physical wellbeing, how much residents were integrated into their community, which included taking part in social or community activities, the range or frequency of community or social activities. It couldn’t find a clear difference to the measures of inclusion of family members in social network.

They did find a difference in the proportion of individuals seeing a dentist (p<0.005) and an increase in the Health Care Scale score (p<0.05) due to improvements in both receipt of healthcare and improved lifestyle (p65).

What worked well?

The equipment could mean that staff could do more, like leave the house and take another resident out for activities as they would be able to have alerts sent to their mobile phones. The equipment was discrete and allowed for more privacy and independence for the residents. An example was given of bed sensors which meant that staff didn't have to disturb people while they were sleeping to check on them.

What got in the way?

The authors reported that sometimes technology wasn't suited to the abilities of the people it was intended for. They gave an example of a fingerprint recognition door entry system that was too difficult for a resident to use. Once it was adapted so that it could recognise the person's hand, and not just the finger, it was possible to use it.

Sometimes the equipment didn't work properly to begin with, or gave off false alarms.

Costs

In this study, the cost of the communal telecare equipment was £2.89 per week for each resident and the cost of individual alarms and sensors was a flat rate of £344 per resident per year (2007 prices).

Considerations

The study might not have had enough people in it to tell if the assistive technology made a big difference or not, and without a group to compare to it's not possible to know if any such differences were definitely because of the assistive technology and not for some other reason. It was also looking at a relatively short period of time, and some good effects might take a longer time to show.

On the other hand, people said that they generally liked the assistive technology, once the 'teething troubles' had been sorted out.

Perry J, Firth C, Puppa M et al. (2012) Targeted support and telecare in staffed housing for people with intellectual disabilities: impact on staffing levels and objective lifestyle indicators

Organisations the authors were involved with:

1. Welsh Centre for Learning Disabilities, Cardiff University
2. Community Lives Consortium, Swansea, UK

Type of study: Impact on costs evaluation

Country: UK

Population: Adults with a learning disability

Quality score:-

Type of service: Telecare

Aim

The study analysed the impact of introducing assistive technology to improve targeting of staff support for individuals with intellectual disabilities living in community residential settings in 2 local authorities. The study comprises n=91 individuals in n=33 different settings.

Background

In preparation for providing assistive technology, intervention group managers were trained and informed about available assistive technologies and the role of support workers and support coordinators. The amount of telecare and adjusted levels of support for each setting was decided in consultation with individuals and their support teams through the care management process. Amendments were made if needed. Telecare devices varied and could be tailored to individual-specific needs. The introduction of telecare with a revised plan for targeted support meant there were 2 sets of workers. The first had a close working relationship and skills closely matching individuals' needs. The second were workers from peripatetic teams with general skills and could provide assistance as needed. Most telecare was passive, triggered by certain behaviours or situations, although some telecare required individual prompting. For examples, refer to the research for further detail. In this study, the cost of the communal telecare equipment was £2.89 per week for each resident and the cost of individual alarms and sensors was a flat rate of £344 per resident per year (2007 prices).

Methods

The study design compares n=63 individuals in 25 settings who received the intervention to n=28 individuals in 8 settings who continued with 'care as usual' and did not receive the intervention. These individuals belong to 1 of 4 networks, of which 3 networks were in the intervention group. The intervention is delivered to the 3 networks at staggered intervals, meaning that the results are collected at different times.

Sample characteristics

The sample's average age was 47 years (range 21-84, sd=12.4), gender was almost evenly split, and all but one individual was white. Previous residential setting varied, with the majority having lived at the family home, in another group home, or specialist learning disability hospital, hostel, or respite care, or 'other', and a small minority lived independently (2%). The sample's average stay in current accommodation was 82.7 months (range = 6-186, sd=54.4).

The intervention and comparison groups had similar scores on the Challenging Behaviour Checklist (p=0.23): intervention (23.5, range=0–73, sd=23.3), comparison (34.2, range=0–117, sd=38.2).

The intervention and comparison groups were statistically different in the following areas:

on the Adaptive Behaviour Scale (p<0.001, with the intervention group having higher scores (191, range=27–306, sd=64.1) than the comparison group (106, range=25-303, sd=79.9)

size of setting (p<0.05), with the intervention group having an average of 2.7 places per setting (range 1-5) compared to 3.8 places in the comparison group (range 1-5).

Because the intervention and control groups differed on level of adaptive behaviour, and research has shown that different levels of adaptive behaviour have significant effects on quality of life, the authors decided not to compare intervention and comparison groups. Instead, results are reported as a before-and-after cohort design for the 3 networks receiving the intervention. Outcomes were collected between 3-5 months post-intervention.

Outcomes

- Outcomes measured include setting descriptors and quality of care. This includes: hours of staffing (measured by the total number of paid staff support for all residents within a setting),
- home-likeness as measured by the Characteristics of the Physical Environment Scale (CPE),
- staff organisation, including planning for individuals, assessment and teaching (measured by the Residential Services Working Practices Scale (RSWPS).

- Other outcomes include objective lifestyle indictors, including:
- health (weight, height, smoking, alcohol use and diet were collected, and body mass index),
- safety using the Risks Scale,
- benefits and income using the Client Services Receipt Inventory (CSRI),
- money management using the Money Management Scale (MMS),
- range and frequency of social and community activities using 2 measures (Index of community involvement and a measure of community participation by Stancliffe and Keane (2000)),
- degree of independence in participation household activities measured by the Index of Participation in Domestic Life (IPDL), and
- choice, as measured by the Choice Questionnaire.

Findings

Pre-intervention, average hours per person ranged from 86.5 to 81.7 hours per week. Post-intervention, staffing hours fell by 14% to 73.3 hours per person per week. This difference was statistically significant ($p<0.05$).

Across all but two outcome measures, post-intervention results were not different to pre-intervention results. This was a statistically significant increase in the proportion of individuals visiting a dentist (p<0.005) and an increase in the Health Care Scale score (p<0.05) due to improvements in both receipt of healthcare and improved lifestyle (p.65).

Conclusions

The authors note that this is the first experimental study on the use of assistive technology known to them, and that while results are promising, further studies using randomised design with longer follow-up periods are needed to increase confidence in the findings as there are still several uncertainties about the longer-term costs and benefits.

Considerations

The authors report that there are several limitations to this study.

First, due to the short follow-up period (3-5 months post-intervention), it is unclear whether outcomes observed reflect the intervention's success or previous levels of higher levels of staffing.

Second, studies that compare fully-staffed vs. partially staffed group homes found improvements in independent community use and participation in domestic activities, but these were not found in this study. The authors suggest that with only a recent introduction of assistive technology (3-5 months), a longer follow-up period is needed to determine whether there are lagged effects.

Third, the authors hypothesize that for a short follow-up period, perhaps more sensitive measurement instruments are needed. They point to a study by Perry & Beyer (2009) finding no difference on the measure, Index in the Participation in Daily Life but finding a positive impact in service user's informal feedback. The authors also suggest that qualitative data would be a useful addition to cross-check findings on standardised outcome measures.

Fourth, outcomes were based on staff self-report and observations, and it is possible that it staff perceived no change but this may have been different to individual service-user experience. The authors suggest that greater understanding is needed and would require involvement of service users and the input of family and/or advocates.

Another area for further research is to analyse how reduced hours affect support staff activity and distribution of activities. The authors note that, in this study, reductions in staffing hours were mainly ‘supervisory’, i.e. the purpose of staff presence was to react to any problems if they arose. Further research should also measure the balance of activity within peripatetic teams, for instance, time spent planning activities and time spent responding to unplanned events.

In relation to generalisability, the authors note that individuals with a range of adaptive skills were included, even those at the lower end of ability.

The authors also emphasise that hours of staffing support were minimally reduced and was not a complete withdrawal. Furthermore, reductions occurred after a thorough discussion with stakeholders on a case-by-case basis and the intention was to improve targeting of staff support to those with the greatest needs while reducing support where it was unnecessary.

The authors emphasise that telecare should not be imposed in a uniform manner and individuals with intellectual disabilities should be involved in their care plan decisions.

Evidence statements

For details of how the evidence is graded and on writing evidence statements, see Developing NICE guidelines: the manual.

AT1	**Evidence of effectiveness** There was no high quality evidence found of the effectiveness of assistive technology to support independent living for adults with learning disabilities.
AT2	**Acceptability and feasibility of assistive technology** There was no high quality evidence that talked about the acceptability and feasibility of using assistive technology to support independent living for adults with learning disabilities.
EcH21	**Reducing the need for support** There was low to moderate quality evidence from 3 studies that assistive technology could reduce the need for some support. One UK quasi-

	experimental study (Perry et al. 2012 ++) (n=91) focused on adults with various levels of ability and challenging behaviour living in various community residential settings. This study introduced assistive technology for both communal and individual-specific needs and decisions were discussed via care plans and involved several stakeholders. The study found that, in the short-term, only 1 outcome measure improved (1 aspect of health), staffing hours were reduced by 14% and all other outcomes were not changed (setting descriptors and quality of care, objective lifestyle indictors including health, safety, money management, independence in participation household activities, choice, and social and community activities). There is no other information about the impact on wider use of health and social care services as this was not an economic evaluation. There is low quality evidence from 2 studies (Bye and Gibson 2009 + (n=3); Cheshire East Council 2010 + (n=18) using surveys or case study design. They show that assistive technology was able to reduce some or all waking-hours night-time support with sleep-in night-time support, reducing staff-related costs.

For Guideline Committee discussion of the evidence see the Evidence to Recommendations tables in Section 3.7.

Included studies for these review questions

Bye G, Gibson M (2009) A review of assistive technology and its impact. Coventry: Life Path Trust

Cheshire East Council (2010) Cheshire East Council: enabling adults with a learning disability. London: Department of Health. Care Services Efficiency Delivery

Harris J (2010) The use, role and application of advanced technology in the lives of disabled people in the UK. Disability & Society 25, 427–39

Martin S, Kelly G, Kernohan WG et al. (2008) Smart home technologies for health and social care support. Cochrane Database of Systematic Reviews 4: CD006412

Perry J, Beyer S (2009) The impact on objective technology of life outcomes of assistive technology in residential services for people with learning disabilities. Journal of Assistive Technologies 3, 5–14

Perry J, Firth C, Puppa M et al. (2012) Targeted support and telecare in staffed housing for people with intellectual disabilities: Impact on staffing levels and objective lifestyle indicators. Journal of Applied Research in Intellectual Disabilities 25, 60–70

3.7 Evidence to recommendations

When drafting these recommendations, the Guideline Committee considered evidence from different study designs that were most suited for answering each review question. Where there was an absence of reliable research evidence, the Guideline Committee considered were able to invite expert witnesses to give their testimony on selected topics (see Appendix D for further detail) or to explore whether it was possible to formulate a recommendation on the basis of their experience and expertise. The Committee could also formulate research recommendations (see section 2).

The evidence to recommendations tables detail the Committee's considerations when drafting the recommendations.

The Guideline Committee considered the following factors when drafting the recommendations:

- whether there is a legal duty to apply the recommendation (for example, to be in line with health and social care legislation and legal duties)
- the strength and quality of the evidence base (for example, the similarity of the populations being studied and the overall quality rating)
- other considerations, such as equalities issues and likely impact on practice and people's experience.

In general, recommendations that an action 'must' or 'must not' be taken are usually included only if there is a legal duty (for example, to comply with health and social care legal duties and legislation).

Recommendations for actions that should (or should not) be taken use directive language such as 'agree', 'assess', 'calculate', 'ensure’, 'record' or 'take'. Recommendations based on poor or limited evidence, use the word 'consider'.

3.7.1 Summary map of recommendations to sources of evidence

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
Achieving change: strategic planning and infrastructure	
Local leadership	
Recommendations for local authorities and clinical commissioning groups	
1.1.1 Local authorities and clinical commissioning groups should jointly designate a lead commissioner to oversee strategic commissioning of health, social care and education services specifically for all children, young people and adults with a learning disability, including those who display, or are at risk of developing, behaviour that challenges.	GC consensus
1.1.2 Ensure that the lead commissioner: • plans and oversees joined-up commissioning arrangements • has in-depth knowledge and experience of working with children, young people and adults with a learning disability and behaviour that challenges, including knowledge of local services • plans services that take a 'whole life' approach from early childhood onwards and enable smooth transitions.	GC consensus
Joint commissioning and funding	
Recommendations for the lead commissioner (acting on behalf of local authorities and clinical commissioning groups)	
1.1.3 The lead commissioner should ensure that budgets and other resources are pooled to develop local and regional services for children, young people and adults with a learning disability and behaviour that challenges. These should be pooled: • across health, social care and education, and • with neighbouring authorities.	AC9
1.1.4 Consider jointly commissioning the most specialised behaviour support services across areas for children, young people and adults with particularly complex needs.	AC9, AC11
1.1.5 Ensure that funding mechanisms for service providers support creative and flexible community-based responses, for example a 'contingency fund' that service providers can draw on quickly if there is a crisis.	Expert witness testimony DS01

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
Planning and delivering services according to local need	
Recommendations for the lead commissioner (acting on behalf of local authorities and clinical commissioning groups)	
1.1.6 Ensure that service planning and delivery is based on an assessment of current and future service needs using: • the local population prevalence of learning disabilities in children, young people and adults and the proportion who are likely to display behaviour that challenges • an analysis of assessed needs in education, health and social care plans, to provide an early view of likely service needs and enable prevention and early intervention • other sources of information, such as registers of people at risk of admission and other dynamic risk data; disabled children's registers; and records of referrals from liaison and diversion teams, youth offending teams and police.	AC7
1.1.7 Ensure that services are planned and delivered in a way that: • is co-produced with children, young people and adults using services and their families, carers and independent advocates • enables person-centred planning and provision • addresses the needs of different age groups but also takes a 'whole life' approach to planning • includes planning for a range of future housing and employment support needs • integrates health, social care and other relevant services.	AC7
1.1.8 Develop local and regional plans that have a single care pathway and point of access for children, young people and adults with a learning disability and behaviour that challenges and their families and carers. Make sure this is reflected in local authorities' commissioning strategies and key documents such as the Market Position Statement. For further information on how to develop care pathways see organising effective care in NICE's	Int2

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
guideline on challenging behaviour and learning disabilities: prevention and interventions.	
Managing risk	
Recommendation for local authorities and clinical commissioning groups	
1.1.9 Take joint responsibility with service providers and other organisations for managing risk when developing and delivering care and support for children, young people and adults with a learning disability and behaviour that challenges. Aim to manage risks and difficulties without resorting to changing placements or putting greater restrictions on the person.	Expert witness testimony DS02
Quality assurance	
Recommendations for commissioners and service providers	
1.1.10 Ensure services meet set service-level and individual outcomes, and that service providers show evidence of achieving these outcomes. This evidence could include: • satisfaction and quality-of-life ratings of children, young people and adults who have used the service, and their family members, friends and carers • outcomes measured by personalised and validated tools such as the 'measure of processes of care' (MPOC) tool, or the 'patient feedback questionnaire' (PFQ) • a reduction in duration and frequency of behaviour that challenges • stability of placements • participation in education by children and young people • reports on the use of restrictive interventions, including medication • contact time with specialist professionals • evidence from quality reviews and spot checking involving experts by experience • quality checks by user-led organisations.	AC6, AC13, Int1, ECH6, SM12, SM29, SP8, Systematic reviews of views
1.1.11 Inpatient services should provide the evidence in recommendation 1.1.10 in addition to evidence of detailed assessments, treatment outcomes and time to discharge.	AC6, AC13, ECH6, Int1, SM12, SM29, SP8, Systematic reviews of views, Expert witness testimony TC01, TC02, GC consensus
1.1.12 Commissioners should establish a multi-agency group, including experts by experience and	Int2

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
service providers, to monitor the quality of services and the outcomes achieved.	
1.1.13 Service providers should use evidence gathered to continuously improve services. They should record the results and make them available to people who use services, and their families and carers.	SM29
Involving people in commissioning and service improvement	
Recommendation for commissioners	
1.1.14 Commissioners should make use of expertise from experts by experience, to inform decision-making and quality assurance of services.	Int1
1.2 Enabling person-centred care and support	
Involving people with a learning disability and behaviour that challenges	
Recommendations for practitioners working with children, young people and adults and their families and carers	
1.2.1 Practitioners working with children, young people and adults with a learning disability and behaviour that challenges and their family members and carers, should get to know the person they support and find out what they want from their lives, not just what they want from services. For more information on involving people in their care and support see working with people with a learning disability and behaviour that challenges, and their families and carers in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.	Systematic reviews of views, SM15, SM17
1.2.2 Actively involve people with a learning disability in all decisions that affect them. If a person aged 16 or over lacks the capacity to make a decision, staff must follow the Mental Capacity Act 2005.	GC consensus
1.2.3 Assess whether a child or young person under the age of 16 is Gillick competent and work in partnership with all children and young people. Include them in decisions about their treatment and ask them how they would like their families or carers to be involved.	GC consensus
1.2.4 Involve families, friends, carers or independent advocates if this is what the person wants, or where decisions are made in the best interests of a person aged over 16 in line with the Mental Capacity Act 2005. This should be done	Systematic reviews of views, SM15, SM17

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
unless there is a compelling reason not to (for example if there are safeguarding concerns).	
1.2.5 Support children, young people and adults with a learning disability and behaviour that challenges to live where and how they want. Give them support that: • is person centred, reflecting their individual needs and choices and maximising their control • helps them take an active part in all aspects of daily life that they choose, based both on what they can do and what they want to do • takes into account the severity of their learning disability; their developmental stage; any communication difficulties or physical or mental health problems; and their life history • respects their cultural, religious and sexual identity • helps them before problems occur or as soon as they emerge, not just when crisis has been reached • encourages people to speak out if they have any worries • promotes continuity of relationships.	GC consensus Adapted from the aims and principles section of the NICE clinical guideline on Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges
1.2.6 Find out children, young people and adults' information and communication needs, record them and share this information with everyone working with them in line with the Accessible Information Standard.	GC consensus
Recommendation for commissioners and practitioners working with children, young people and adults	
1.2.7 Ensure that people with a learning disability and behaviour that challenges have access to speech and language therapy when they need it.	SM15
Advocacy	
Recommendations for local authorities	
1.2.8 Consider providing access to independent advocacy whenever it is wanted or needed by a person with a learning disability and behaviour that challenges. As a minimum it must be offered by local authorities as described in the Care Act 2014, Mental Capacity Act 2005 and Mental Health Act 2007.	GC consensus

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
1.2.9 Ensure that independent advocates working with children, young people and adults with a learning disability and behaviour that challenges have skills and experience in working with these groups, and in working with specialist learning disability services. See also recommendations 1.8.3 and 1.8.4 on independent advocacy in relation to inpatient admissions.	GC consensus
Coordinating care and support	
Recommendations for local authorities, clinical commissioning groups and service providers	
1.2.10 Local authorities working in partnership with healthcare professionals should assign a single practitioner, for example a social worker (in a disabled children's team or community learning disability team) or community psychiatric nurse, to be the person's 'named worker'. The named worker should get to know the person and coordinate support to meet their needs over the long term.	Int8, SM3, SM11, SM15, SM17, SM33
1.2.11 The local authority, clinical commissioning group and service providers should liaise regularly with the named worker, keeping them informed and involved in decision making.	SM23
Recommendations for the named worker	
1.2.12 Arrange regular meetings to discuss the person's care and support, and invite people in their support network, including family members, carers, independent advocates and practitioners from all services that support them. This could build on existing processes, for example, the education, health and care planning and review process for children (see Gov.uk's children with special educational needs and disabilities).	SM23
1.2.13 Recognise and use the expertise brought by all members of the person's support network (not only those who are paid).	SM23
Care and support planning	
Recommendations for community learning disability teams and service providers	
1.2.14 Community learning disability teams (or relevant children's services, for example disabled children's teams) and service providers should work in partnership with the child, young person or adult, their family members, carers and advocates and their named worker to develop, deliver and	SM3, SM17, SM20

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
review their care and support plan. Develop a care plan that: - meets the person's needs and preferences - works to support and maximise the person's mental capacity - takes into account people's fluctuating mental capacity and needs - adopts a 'whole life' approach that covers what they want to achieve in both the short and long term and supports smooth transitions - takes a positive approach to managing risk - sets out what to do to prevent or respond to a crisis.	
1.2.15 Service providers and agencies responsible for commissioning and planning services (including specialist services) should match the specific skills of staff to the characteristics of the person with a learning disability and behaviour that challenges. Do this as soon as care and support planning begins.	SM24, Expert witness testimony DS03
1.2.16 Community learning disability teams or relevant children's services (for example, disabled children's teams) and service providers should review children, young people and adults' care and support with their named worker: - according to timings agreed in their plan and - whenever there is a significant change, for example, if the person is placed out of area.	Adapted from section 1.6 of NICE's clinical guideline on Challenging behaviour and learning disabilities: prevention and interventions. SM3; Expert witness testimony DS03, Expert witness testimony DS04
1.2.17 When reviewing plans: - involve people as set out in recommendations 1.2.1 to 1.2.4 - take account of people's fluctuating mental capacity - check that staff are following the behaviour support plan recommendations in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions - think about plans for the future, including whether changes might be needed to the person's housing or support.	Adapted from section 1.6 of NICE's guideline on Challenging behaviour and learning disabilities: prevention and interventions. SM3; Expert witness testimony DS03, Expert witness testimony DS04
1.2.18 As soon as a child, young person or adult develops behaviour that challenges, community	GC consensus adapted from 1.6 Behaviour support

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
learning disability teams (or relevant children's services, for example child and adolescent mental health learning disability teams) and service providers should offer to work with them and their family or carers to develop a behaviour support plan. For more information on what this should include, see the recommendations on behaviour support plan in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.	planning section of NICE clinical guideline on Challenging behaviour and learning disabilities: prevention and interventions
Supporting people to use personal budgets	
Recommendations for local authorities and clinical commissioning groups	
1.2.19 Ensure that a range of funding arrangements are available, including direct payments, personal budgets or individual service funds, depending on children, young people and adults' needs and preferences.	GC consensus
1.2.20 Offer people a choice of funding arrangements (see recommendation 1.2.19) and support people to use these budgets, where they wish to, by: • telling them how each element of their support will be funded • telling them how much money is available and how much control they have over how the money is spent • giving them and their families and carers information about different ways of managing their budgets, and how these may affect their carer • supporting them to try out different mechanisms for managing their budget • offering information, advice and support to people who pay for or arrange their own care and support, as well as to those whose care and support is publicly funded • offering information about benefits entitlement • ensuring that carers' needs are taken fully into account. [This recommendation is adapted from NICE's guideline on older people with social care needs and multiple long-term conditions]	Adapted from NICE's guideline on older people with social care needs and multiple long-term conditions Expert witness testimony DS05
Delivering care and support	

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
Recommendations for staff in all settings	
1.2.21 In all settings, staff working with children, young people and adults with a learning disability and their families and carers should aim to reduce the risk of behaviour that challenges developing by: • identifying health or sensory problems early • providing strategies and interventions to support communication. Follow recommendations on psychological and environmental interventions in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.	SM13, SM20, SM23, GC consensus
1.2.22 For people taking medicines: • follow recommendations in NICE's guideline on managing medicines for adults receiving social care in the community and • if the reason for the medicine relates to the person's behaviour or mental health, ensure it is reviewed regularly in line with recommendations on medication in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions and mental health problems in people with learning disabilities: prevention, assessment and management.	GC consensus adapted from NICE's guidelines on managing medicines for adults receiving social care in the community and section 1.8 Medication of the NICE clinical guideline on Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges
1.2.23 Ensure that children, young people and adults with a learning disability and behaviour that challenges know about and are able to use services to support their health and wellbeing. These should include: • services helping people to make and maintain friends, relationships and social networks in their community and take part in community activities • access to employment and pre-employment opportunities • day opportunities where activities can be tailored to the person's interests, preferences, strengths and abilities • universal healthcare services and health checks • peer support opportunities.	ECU2, Int12, SM21, SM22, Expert witness testimony HPBS05, expert witness testimony TC01
1.3 Early intervention and support for families and carers	
See section 1.6 for more recommendations on services for children and young people.	

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
Recommendations for local authorities	
1.3.1 Ensure that families and carers of children, young people and adults with a learning disability and behaviour that challenges are given support that helps them to: • manage their role as carers • care for the person and meet their needs, in relation to behaviour, care and support, communication, physical health, mental health, educational needs or any offending behaviour • access support from specialist services when needed.	SM13, Expert witness testimony HPBS01
1.3.2 Provide information, guidance and ongoing support for families and carers of children, young people and adults with a learning disability and behaviour that challenges which address different aspects of their life. Sources of support could include: • peer support • parent and carer groups or forums • email support • individual phone and face-to-face support • family networks • independent advocacy • managed email networks (a shared discussion forum) • social media groups.	SM10, SM30, SM31
1.3.3 Give family members and carers information in line with support and interventions for family members or carers in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions. This could be in the form of a 'welcome pack'. Provide this information: • at the first point of contact with families • through the local authority website, local libraries and universal services such as GP surgeries.	AC2, Int9, SM10, SM17, SM36
Recommendations for the named worker	
1.3.4 Help people and their families to understand information about available support (see recommendation 1.3.3) from first contact onwards.	AC2, Int9, SM10, SM17, SM36

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
1.3.5 Advise family members and carers how to access: • short break services • specialist behaviour support • training as set out in recommendations 1.7.1 and 1.7.2 in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions. • support in an emergency • community resources, including voluntary organisations, networks and support groups • local safeguarding procedures, including how to raise safeguarding concerns or make a complaint.	AC2, EcAC4, Int9, SM10, SM14, SM17, SM23, SM28, SM36. Adapted from recommendations in NICE's guideline on Challenging behaviour and learning disabilities: prevention and interventions.
1.3.6 Ensure that family members and carers have information such as contact details of staff and key dates and appointments.	AC2, Int9, SM10, SM17, SM36
1.4 Services in the community - prevention, early intervention and response	
Developing services in the community	
Recommendations for the lead commissioner (acting on behalf of local authorities and clinical commissioning groups)	
1.4.1 The lead commissioner should commission services in the community for people with a learning disability and behaviour that challenges (including for people in contact with, or at risk of contact with, the criminal justice system). These services: • should be able to cater for lower-level needs up to intensive, complex or fluctuating needs • could be set up either as 1 large team with different subteams or as several separate teams • should be provided wherever possible as an alternative to, and to reduce the potential need for: - inpatient care for children, young people and adults or - residential placements for children and young people.	AC6, AC11, AC14, AC19, ECU4, Int2, Int4
1.4.2 Services in the community should fulfil the following core functions:	AC6, AC11, AC14, AC19, ECU4. SM23. The training and support recommended in the NICE guideline on

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
- specialist prevention and early intervention - developing capacity in non-specialist community services to prevent unnecessary inpatient admissions - giving support and training to families and carers (by following the recommendations on support and interventions for family members or carers in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions) - quality assurance and service development - short-term assessment and intervention - longer-term complex intervention - crisis response and intervention.	challenging behaviour and learning disabilities: prevention and interventions.
1.4.3 Ensure that children, young people and adults with a learning disability can get specialist support through their community learning disability team that meets their needs, for example in relation to: - behaviour - communication - social care and support needs - physical health - mental health - education - offending behaviour. This could be achieved by employing relevant practitioners within the community learning disability team or by developing close links with practitioners in other relevant services.	AC11, Int2, Int4
Recommendations for community learning disability teams and service providers	
1.4.4 Services who provide support through the community learning disability team should work together and provide consultancy and support to each other. They should work with children, young people and adults and their family members and carers in a way that is: - personalised - flexible - responsive - accessible - reflective.	Int2, Int5, Int12

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
1.4.5 If a child, young person or adult develops, or is at risk of developing, offending behaviour, community learning disability teams should refer them to appropriate specialists, such as community forensic or youth justice services, as soon as possible (see recommendations 1.4.12 to 1.4.16). These services should: • provide evidence-based early interventions that are adapted for people with a learning disability and address the specific behaviour • work in an ongoing partnership with each other and with the community learning disability team whenever needed.	AC12, AC13
1.4.6 Community learning disability teams should maintain good communication and links with the police and liaison and diversion teams so that: • they can advise on assessments of vulnerability, particularly for people with mild or borderline learning disabilities who may otherwise not be identified as vulnerable • people who need support can be diverted from the criminal justice service to community learning disability teams.	AC12, AC13
Specialist behavioural support	
Recommendations for the lead commissioner (acting on behalf of local authorities and clinical commissioning groups)	
1.4.7 Ensure that specialist assessment and behavioural support are available in the community so that children, young people and adults can stay where they currently live and avoid moving.	AC9, SM14, Expert witness testimony HPBS02
1.4.8 Ensure that specialist services for behaviour that challenges are available to everyone with a learning disability and behaviour that challenges, based on an assessment of each person’s need and risk and taking into account the benefit of early intervention.	AC10, Int4
1.4.9 The lead commissioner should: • set local maximum waiting times for initial assessment, and for urgent and routine access to treatment and support • ensure that waiting times for specialist behavioural support do not exceed NHS waiting time standards.	AC10, Int4

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
Intensive behavioural support during a crisis	
Recommendations for local authorities, clinical commissioning groups, community learning disability teams and specialist services	
1.4.10 Provide a local, personalised response to children, young people and adults who need intensive support during a crisis. This response should: • focus on keeping people in their own home • have an out-of-hours helpline as a first option with the capacity to respond rapidly (within 1 hour or in line with local mental health crisis response times), staffed by people with skills and knowledge in learning disabilities and behaviour that challenges, and specialist skills in mental health problems • provide face-to-face support within 4 hours if needed, based on initial triage • involve partnership with other commissioners, service providers and family members and carers • include giving staff access to the person's information if they are already in contact with services • provide short-term support to achieve aims that are agreed with the person • include clear contact details for children's services (as set out in the Local Offer) and adults' services.	ECU4, SM14, SM23, SM28, Expert witness testimony HPBS03
1.4.11 Use a clear, coordinated approach to reducing the level of support from more intensive services in line with the person's needs. Learn from what happened and use this knowledge to inform future early intervention and prevention services and support crisis plans.	AC10, Expert witness testimony HPBS04
Services for people in contact with, or at risk of contact with, the criminal justice system	
Recommendation for local authorities and clinical commissioning groups	
1.4.12 Commission local community forensic services for children, young people and adults with a learning disability and behaviour that challenges who are in contact with, or at risk of contact with, the criminal justice system to prevent out-of-area hospital placement. These could be provided as stand-alone teams, or as a specialism within an existing team, for example a community learning	AC6, SP8

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
disability team, or a learning disability specialism within a community forensic team.	
Recommendations for service providers, including forensic services	
1.4.13 When forensic community learning disability services are supporting children, young people and adults with a learning disability (for example, if they are subject to a forensic community rehabilitation order or a community treatment order) they should enable them to live in the community, as close to home as possible, and in the least restrictive setting.	SP8, SP9
1.4.14 Forensic community learning disability services should stay in frequent contact with the person they are supporting, including those who are in out-of-area placements or criminal justice settings, and help them build and maintain social links in their community.	SP9
1.4.15 Forensic learning disability services and probation services should work together to agree who is best able to support the person in meeting the requirements of their treatment or rehabilitation order.	Int3, SP9
1.4.16 Forensic learning disability services, mental health, specialist voluntary sector organisations, learning disability services and social care services should establish care pathways and close links with each other to help them refer people quickly between these services to get the right support and effectively manage risk.	Int4, SP8
1.5 Housing and related support	
Giving people a choice of housing	
Recommendations for local authorities, clinical commissioning groups and service providers	
1.5.1 Commissioners should work with local housing and social care providers to identify the specific housing needs of adults with a learning disability and behaviour that challenges. They should ensure areas have a range of housing and care options available that meet these needs and cater for different preferences and person-centred support needs (see also section 1.2).	EcH1, EcH2, EcH3, EcH12, EcH13, EcH17, EcH19, EcH23 and expert witness testimony DS06
1.5.2 Enable adults to live close to their family, friends and community unless they choose not to or there is a compelling reason not to.	SM18

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
1.5.3 Where possible ensure that, wherever people live, they have security of tenure in line with the Real Tenancy Test.	Expert witness testimony DS06
1.5.4 When helping adults with a learning disability and behaviour that challenges choose where to live: • provide information on the range of possible options • take into account their preferences and any specific support needs or risks, including the impact of environmental factors on the person (see the recommendation on environmental factors in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions) • give them advice on adapting their current home if needed.	EcH1, EcH2, EcH3, EcH12, EcH13, EcH17, EcH19, EcH23 and expert witness testimony DS06, expert witness testimony DS07
1.5.5 Offer people the option to live alone with appropriate support if they prefer this and it is suitable for them.	EcH1, EcH2, EcH3, EcH12, EcH13, EcH17, EcH19, EcH23 and expert witness testimony DS06, expert witness testimony DS07
1.5.6 If adults prefer not to live alone with support, or it is not suitable for them, offer them the option of living with a small number of other people in shared housing that has a small-scale domestic feel. Involve people in choosing how many people, and who, they live with.	EcH16, EcH17, EcH18.
1.5.7 Offer adults housing outside their local community only: • if it is what the person wants • if it is indicated after a full assessment and planning process, which takes into account the person's preferences, needs and risks • for a specified time that has been agreed with the person, or agreed in their best interests if they lack capacity to decide this – for example if they are in crisis and there is no local placement available.	SP3 from review question 2.1 and EcAC1, EcAC2, EcAC3, EcH5, EcH8, EcH6, EcH9, EcH10, and EcH11, GC consensus
1.5.8 If someone is moving outside their local area, local authorities, clinical commissioning groups and commissioners should:	AC8, Int9, SP3,

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
• establish the commissioner who is responsible for paying for the person's care and support • ensure they will still have the support they need • make a plan that enables them to return to their local area if they want to, or if it is in their best interests if they lack capacity to decide this.	
1.6 Services for children and young people	
Recommendations for local authorities, clinical commissioning groups and the lead commissioner	
1.6.1 Local authorities should ensure that parents and carers of children and young people with a learning disability and behaviour that challenges have support to care for their child (see section 1.3)	AC9 and GC consensus
1.6.2 Local authorities must promote the upbringing of children and young people with a learning disability and behaviour that challenges by their families, in line with section 17 of the Children Act 1989. This should include providing a range of services including education, and general and specialist learning disability support services in the community, as an alternative to residential placements away from home and to reduce the potential need for such placements.	SM10
1.6.3 The lead commissioner should ensure that specialist behavioural support in the community for children and young people includes support from education and child and adolescent mental health service (CAMHS) practitioners who have skills and experience in working with children and young people with a learning disability and behaviour that challenges.	AC9
Recommendations for local authorities, service providers and practitioners	
1.6.4 Health, mental health and behaviour support practitioners should work with other services, for example education and social care, to: • deliver the outcomes agreed in a child or young person's education, health and care plan • provide support and interventions in line with NICE's guideline on challenging	SM12

<table>
<tr><th>Recommendation</th><th>Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)</th></tr>
<tr><td>behaviour and learning disabilities: prevention and interventions
- maximise life opportunities for children and young people, including by ensuring they have access to meaningful education
- support smooth transitions between services in line with organising effective care in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions
- support children and young people to develop skills for independence
- take a positive approach to managing risk.
This applies to children and young people in residential placements, as well as those living at home.</td><td></td></tr>
<tr><td>1.6.5 If a child or young person's behaviour that challenges is deteriorating or causing concern, the local authority should carry out a multi-agency review of their education, health and care plan (or other relevant plan) and involve the child or young person and their parents or carers. Review whether the plan needs to be updated and additional support provided if the child or young person's needs have changed.</td><td>SM12</td></tr>
<tr><td colspan="2">Exploring alternatives to residential placement</td></tr>
<tr><td colspan="2">Recommendations for the lead commissioner, service providers and practitioners</td></tr>
<tr><td>1.6.6 Support parents and carers to understand the full range of options for education, care and support for their child.</td><td>GC Consensus</td></tr>
<tr><td>1.6.7 When considering a residential placement, arrange a multi-agency review to explore all options and to review the child or young person's education, health and care plan. Include in this discussion:</td><td>GC consensus</td></tr>
</table>

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
• the child or young person and their parents or carers • the lead commissioner on behalf of the local authority and clinical commissioning group • at least 1 practitioner with clinical expertise in learning disability and the specific behaviour that is challenging • an independent expert by experience • special educational needs staff, or staff from their school or college.	
1.6.8 Only offer children and young people a residential placement: • if assessment and care planning show that their needs (including their educational needs) cannot be met while they are living at home, and all alternatives to residential care have been considered and exhausted, or • following a request by the child or young person's family, which has been considered under the Children and Families Act 2014.	SM10, GC consensus
Living in residential placements	
Recommendations for local authorities, clinical commissioning groups and service providers	
1.6.9 Commission residential placements for children and young people as close to home as possible. Take into account in local authority contracts that some families may need financial support to help them see their child and for their child to visit them.	SM8, GC consensus
1.6.10 Support children and young people to maintain links with their family, friends and community (for example, members of their religious community) while they are in a residential placement.	SM8, GC consensus
1.6.11 Local authorities and service providers must promote maximum contact between children and young people living in residential placements and their family members and carers (in line with schedule 2 of the Children Act 1989). If a placement lasts longer than 3 months the Visiting Regulations 2011 must be followed, for both local and out-of-area placements. Help families stay in touch between visits, for example using Skype.	SM8, GC consensus

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
Planning and review to support children and young people leaving a residential placement	
Recommendations for local authorities, clinical commissioning groups and practitioners	
1.6.12 As soon as a child or young person moves into a residential placement local authorities and clinical commissioning groups should ensure that: • a plan is developed for how they will progress towards returning to their family home, if appropriate, and towards greater independence • they continue to be supported to meet the outcomes identified in their education, health and care plan.	GC consensus
1.6.13 Review the plan in recommendation 1.6.12 at least every 6 months to check that progress is being made. This could be done as part of a looked-after child review, an education, health and care plan review, or sooner if needed.	GC consensus
1.6.14 Plans should be reviewed by the practitioner responsible for overseeing the child or young person's education health and care plan and all other practitioners involved in their care and support, including a specialist in behaviour that challenges.	GC consensus
1.6.15 If progress towards the outcomes in the plan has not been made, explore and address the reasons for this. If the child, young person or their family disagrees with the decision made at the review meeting, explain how they can challenge the decision if they want to.	AC20
1.7 Short break services	
Recommendations for local authorities, commissioners and service providers	
1.7.1 Local authorities must, in line with the Breaks for Carers of Disabled Children Regulations 2011 and the Children and Families Act 2014: • provide a range of short breaks for children and young people with a learning disability and behaviour that challenges, and • publish as part of their Local Offer a statement of the range of services available and how eligibility will be assessed.	AC1, SM12, SM36, SM37, SP5
1.7.2 Commissioners in health and social care should provide sufficient, reliable, flexible and varied short break options, including both breaks	AC1, SM12, SM36, SM37, SP5

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
away and support at home, for adults with a learning disability and behaviour that challenges.	
1.7.3 Ensure that short breaks are: • community-based and close to home • available based on need, and at short notice both in crisis and to prevent a crisis • tailored to the needs of the person and their family or carers, taking into account the person's interests and preferences • able to provide a positive experience for the person being supported • able to deliver what is agreed in the education, health and care plan or care and support plan; carer's assessment; or behaviour support plan • planned in advance wherever possible and involve people and their family members and carers visiting the service first to see if it is suitable and to get to know the staff providing it • provided by staff who understand and respect people's cultural norms and values and their choices about personal care, private life and lifestyle.	AC1, AC3, SM12, SM36, SM37, SP5
1.8 Making the right use of inpatient services	
Exploring alternatives to inpatient admission	
Recommendations for commissioners, service providers and practitioners	
1.8.1 Admit children, young people and adults with a learning disability and behaviour that challenges to inpatient units only if assessment and care planning show that their needs cannot be met safely in the community, and all possibilities for doing so have been considered and exhausted.	AC1, AC6, AC11, AC19, AC23, SM18. Supported by , expert witness testimony IP01, expert witness testimony DS08
1.8.2 When thinking about inpatient admission, arrange a discussion to explore all other viable options. Include in this discussion:	GC consensus, Expert witness testimony IP01.

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
- the person and their family members and carers - at least 1 practitioner with clinical expertise in learning disability and the specific behaviour that is challenging - at least 1 independent expert by experience. For further guidance, see NHS England's information on community Care and treatment reviews or, for children and young people, a community Care, education and treatment reviews.	
Providing information	
Recommendations for local authorities, clinical commissioning groups and service providers	
1.8.3 When there is a possibility that someone will be admitted to hospital, including as an informal admission, local authorities and clinical commissioning groups should give them and their family and carers accessible, independent information and advice about their rights, access to independent advocacy and other possible options for treatment, and care and support.	GC consensus, expert witness testimony DS08
1.8.4 Service providers must provide information about independent mental health advocacy as required by the Mental Health Act 1983.	GC consensus
When a placement is needed	
Recommendation for local authorities and clinical commissioning groups	
1.8.5 Provide an inpatient placement that is as close as possible to where the person usually lives.	AC10, AC18, SM31, SM32
Recommendations for inpatient services and community learning disability teams, including the named worker	
1.8.6 The named worker should support the person to maintain links with their family, friends and community (for example, members of their religious community) while they are in hospital, and give their family and friends information about their progress.	AC10, AC18, SM31, SM32 GC consensus
1.8.7 If people are admitted as inpatients outside their local area, social workers in the community learning disability team and the named worker should stay in contact with the person, and help them stay in contact with other key practitioners in their own area.	AC10, AC18, SM31, SM32, GC consensus
1.8.8 When someone is admitted as an inpatient, offer them interventions in line with recommended	AC6

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
psychological and environmental interventions in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions. Ensure that these interventions specifically address their needs and the reason for their admission.	
Planning and review to support discharge	
Recommendations for inpatient services and community learning disability teams	
1.8.9 As soon as the person is admitted, the hospital and community learning disability team should work together to develop a discharge plan.	AC20 and supported by expert witness testimony DS08 and IP02.
1.8.10 Practitioners involved in the child, young person or adult's care and support should review the person's discharge plan at least every 3 months. Include in these reviews: • the person and their family members or carers • the practitioner responsible for agreeing discharge • a specialist in behaviour that challenges.	AC20
1.8.11 Think about using the Care and treatment review process or Care programme approach as a framework for reviews to support discharge for adults. For children and young people think about using the Care, education and treatment review or education, health and care planning process.	AC20
1.8.12 If the person is not discharged after the meeting with practitioners involved in their care and support, provide sufficient reason for this and develop a new plan towards discharge. Explain to the person and their family or carers how they can challenge the decision if they want to.	AC20
1.8.13 Tell people who might apply to, or are referred for, a first-tier mental health tribunal relating to being an inpatient, about their right to request an independent clinician (in line with section 76 of the Mental Health Act 1983) to: • visit them at any reasonable time and examine them in private • inspect any records relating to their conditions and treatment.	GC consensus
1.9 Staff skills and values	
Recommendations for commissioners, local authorities and service providers	

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
1.9.1 As part of staff recruitment and training, ensure that staff have the skills, knowledge and qualities they need to support children, young people and adults they are working with. This includes: • the skills and knowledge recommended in staff training, supervision and support in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions. • being resilient and compassionate • showing that they care • understanding and respecting the person's human rights, faith, culture, identity and values.	SM7, SM15, SM16, SM26, expert witness HPBS06, expert witness testimony DS03
1.9.2 Ensure that staff providing direct support to children, young people and adults with a learning disability and behaviour that challenges have the 'direct contact' level competencies of the Positive Behavioural Support Academy's Positive behaviour support competence framework.	SM7, SM15, SM16, SM26
1.9.3 Give staff providing direct support access to advice from behaviour support specialists with 'consultant' level competencies of the Positive Behavioural Support Academy's Positive behaviour support competence framework.	SM7, SM15, SM16, SM26
1.9.4 Local authorities and clinical commissioning groups should plan for and resource training among service providers who provide day-to-day support about how to work with young people and adults with a learning disability who are at risk of offending.	AC13
1.9.5 Organisations should ensure that staff have supervision and support, in line with the recommendations on staff training, supervision and support in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.	SM15, SM16, SM30
1.9.6 Involve young people and adults with a learning disability and behaviour that challenges in staff recruitment. Involve their family members and carers too if the person agrees, unless there is a compelling reason not to.	SM16
1.9.7 Think about how to involve children with a learning disability in staff recruitment.	SM16

3.7.2 Evidence to recommendations

Topic/section heading	Achieving change
Recommendations	Recommendations for local authorities and clinical commissioning groups 1.1.1 Local authorities and clinical commissioning groups should jointly designate a lead commissioner to oversee strategic commissioning of health, social care and education services specifically for all children, young people and adults with a learning disability, including those who display, or are at risk of developing, behaviour that challenges. 1.1.2 Ensure that the lead commissioner: • plans and oversees joined-up commissioning arrangements • has in-depth knowledge and experience of working with children, young people and adults with a learning disability and behaviour that challenges, including knowledge of local services • plans services that take a 'whole life' approach from early childhood onwards and enable smooth transitions. Joint commissioning and funding Recommendations for the lead commissioner (acting on behalf of local authorities and clinical commissioning groups) 1.1.3 The lead commissioner should ensure that budgets and other resources are pooled to develop local and regional services for children, young people and adults with a learning disability and behaviour that challenges. These should be pooled: • across health, social care and education and • with neighbouring authorities. 1.1.4 Consider jointly commissioning the most specialised behaviour support services across areas for children, young people and adults with particularly complex needs. 1.1.5 Ensure that funding mechanisms for service providers support creative and flexible community-based responses, for example, a contingency fund that service providers can draw on quickly if there is a crisis. Planning and delivering services according to local need Recommendations for the lead commissioner (acting on behalf of local authorities and clinical commissioning groups) 1.1.6 Ensure that service planning and delivery is based on an assessment of current and future service needs using: • the local population prevalence of learning disabilities in children, young people and adults and the proportion who are likely to display behaviour that challenges • an analysis of assessed needs in education, health and social care plans, to provide an early view of likely service needs and enable prevention and early intervention • other sources of information, such as registers of people at risk of admission and other dynamic risk data; disabled

	children’s registers; and records of referrals from liaison and diversion teams, youth offending teams and police. 1.1.7 Ensure that services are planned and delivered in a way that: • is co-produced with children, young people and adults using services and their families, carers and independent advocates • enables person-centred planning and provision • addresses the needs of different age groups but also takes a 'whole life' approach to planning • includes planning for a range of future housing and employment support needs • integrates health, social care and other relevant services. 1.1.8 Develop local and regional plans that have a single care pathway and point of access for children, young people and adults with a learning disability and behaviour that challenges and their families and carers. Make sure this is reflected in local authorities’ commissioning strategies and key documents such as the Market Position Statement. For further information on how to develop care pathways, see organising effective care in NICE’s guideline on challenging behaviour and learning disabilities: prevention and interventions.
Research recommendations	What is the effectiveness and cost effectiveness of different resource allocation models of services over the lifespan for people with learning disabilities and behaviour that challenges?
Review questions	2.1. What is the appropriate community-based (including residential care) service capacity for children, young people and adults and carers? 2.2. What is the appropriate inpatient bed capacity (local and out of area) for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 5.1. What mechanisms enable effective joined-up working between education, health and social care service providers supporting children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers?
Quality of evidence	For review questions 2.1 and 2.2, there was little direct research evidence about the appropriate service capacity for inpatient or community services. In the absence of direct evidence, the review team included studies that might provide some insights in to how the whole system currently works or does not work. The studies included views and experiences studies of the barriers and facilitators identified by professionals and people who use services, process evaluations about implementation and secondary analysis of administrative data providing patterns of service use and to identify potential service needs. The evidence for review question 5.1 was underpinned by a combination of different study designs that report on the mechanisms for joint working between services and between people and their families.

	They reflect findings from a range of studies, of varying quality and design. These recommendations on 'achieving change' are the potential solutions to problems and issues identified in the indirect evidence of barriers and facilitators to access, studies of views and experiences, expert witness testimony and the Guideline Committee's experiential and practice based knowledge. Recommendation 1.1.3 was based on review question 2.1 evidence statement AC9 on shared commissioning, which was based on 4 low quality studies. Recommendation 1.1.4 was based on review question 2.1 and evidence statement AC11, which comprised 4 survey studies, 1 moderate quality and 3 low quality. It was supported by evidence on shared commissioning AC9, which was based on 4 low quality studies. Recommendation 1.1.5 was based on expert witness testimony DS01. Recommendations 1.1.6 and 1.1.7 were based on review question 2.1 , 1 evidence statement AC7 on local recording systems, comprising 3 low quality studies. Recommendation 1.1.8 was based on review question 5.1 , 1 evidence statement Int2 on drawing in expertise from other organisations, based on 5 studies, 1 moderate quality and 4 poor quality. There was no direct research evidence on the effectiveness of an integrated regional challenging behaviour services. In the absence of research evidence in this area, the committee has made a research recommendation about the effective components and barriers and facilitators related to developing an integrated regional challenging behaviour service across health and social care. There was also a lack of research evidence on effectiveness and cost effectiveness of different resource allocation models over the lifespan and the Guideline Committee made a research recommendation in this area.
Economic considerations	There was no cost effectiveness evidence identified to support these recommendations. However, the Guideline Committee were mindful of economic considerations when making the recommendations. With regard to the single lead commissioner role (recommendations 1.1.1 and 1.1.2) the committee considered that this role may not exist in a number of local areas, and therefore may be associated with some resource impact. However, the view of the committee was that having a single individual with oversight of commissioning could lead to better use of resources in terms of having a long term view of what people were likely to need, and thereby preventing them from going in to crisis and requiring more intensive services. There was no cost-effectiveness evidence in relation to pooled budgets (recommendation 1.1.3). However, the view of the committee was that this should reduce duplication and therefore increase efficiency.

	There was no cost-effectiveness evidence in relation to 1.1.4 However, the aim of this recommendation was to acknowledge that it may not be a realistic use of resources for each local area to individually commission the most specialist services. There was no cost-effectiveness evidence in relation to the use of contingency funds. The expert witness testimony suggested that this related to speed of access to funding, rather than giving providers additional funding. Recommendations 1.1.6 and 1.1.7 assumed making better use of existing sources of data, and so were not expected to have significant resource impact. Identification of individuals and planning appropriate services is an investment. If effective identification and planning occur, this has the potential to lead to the provision of the right services which match individuals' needs, which can lead to better outcomes and more efficient use of resources. There was no cost-effectiveness evidence in relation to recommendation 1.1.8. However, the committee noted that having a clear care pathway should help to use resources more effectively.
Evidence statements – numbered evidence statements from which the recommendations were developed	AC7 (recommendation 1.1.6 and 1.1.7) AC9 (recommendation 1.1.3 and 1.1.4) AC11 (recommendation 1.1.4) DS01 (recommendation 1.1.5) Int2 (recommendation 1.1.8)
Other considerations	Recommendations 1.1.1 and 1.1.2 were based on GC consensus and are the potential solutions to problems and issues identified in the indirect evidence of barriers and facilitators to access, studies of views and experiences, expert witness testimony and the Guideline Committee's experiential and practice based knowledge. The view of the committee was that a single dedicated commissioner for learning disabilities whose portfolio included people with learning disabilities and behaviour that challenges would be a good mechanism for achieving greater integration. The view of the committee was that this person should bring together commissioning across health and social care, and for both children and adults. It was the view of the committee that this individual should have some direct experience of working with people with learning disabilities to inform their commissioning role. Following stakeholder feedback that the lead commissioner role was potentially extremely broad, the recommendation was amended using GC consensus to clarify that, whilst the commissioning function for this population should be overseen by one individual, this function could comprise broader joined-up commissioning arrangements to ensure a range of skills and sufficient capacity. The GC also clarified that part of the purpose of the commissioner was to ensure that commissioning support smooths transitions (recommendation 1.1.2).

	Recommendations 1.1.3 and 1.1.4 were based on evidence statement AC9 which related to shared commissioning and pooled budgets. The evidence suggested that a lack of mechanisms for pooling budgets was a barrier to commissioning appropriate local services, and led to reliance on out of area placements. This recommendation also addressed the needs of people with different degrees of disability (a group highlighted through the Equality Impact Assessment). Recommendation 1.1.3 was also based on evidence statement AC11 which included evidence about the need for people with learning disability and behaviour that challenges to be able to access specialist service integrated with general services. Recommendation 1.1.5 was based on expert witness testimony DS01, from a commissioner and provider evidence statement talking about successfully moving people from inpatient settings in to the community. They thought that one of the aspects of their practice that helped this was funding arrangements which enabled providers to have quick access to ‘contingency funds’ if a person’s behaviour deteriorated and they required extra support, rather than the provider having to wait for additional funding from the commissioner. This meant they were able to act quickly to prevent a more restrictive placement or admission to hospital. Recommendations 1.1.6 and 1.1.7 were based on evidence statement AC7, which found that services are not always planned according to local need, partly due to a paucity of accurate recording systems. The committee recommended a number of existing sources of information that should be taken in to account based on their professional and personal experience. They also aimed to highlight the importance of forward planning to think about the future needs of people in the local population with learning disability and behaviour that challenges, particularly as many young children will have specific conditions that means they are likely to require long term support. These recommendations addressed the needs of different age groups (a group highlighted through the Equality Impact Assessment). Reference to dynamic risk data and disabled children's registers was added to recommendation 1.1.6 based on GC consensus following stakeholder consultation. Reference to co-production and integration were added to recommendation 1.1.7 based on GC consensus following stakeholder consultation. Recommendation 1.1.8 was based on evidence statement Int2 which related to partnership working and drawing in expertise from different teams. The view of the committee was that people can experience barriers to accessing services if they ‘fall between the gaps’ in the entry criteria for different services. The view of the committee was that having a single care pathway and single point of access to services would prevent this from happening. Reference to inclusion in the Market Position Statement was added based on the professional experience of committee members.

Topic/section heading	**Managing risk and quality assurance**
Recommendations	Recommendation for local authorities and clinical commissioning groups 1.1.9 Take joint responsibility with service providers and other organisations for managing risk when developing and delivering care and support for children, young people and adults with a learning disability and behaviour that challenges. Aim to manage risks and difficulties without resorting to changing placements or putting greater restrictions on the person. Quality assurance Recommendations for commissioners and service providers 1.1.10 Ensure services meet set service-level and individual outcomes, and that service providers show evidence of achieving these outcomes. This evidence could include: • satisfaction and quality-of-life ratings of children, young people and adults who have used the service, and their family members, friends and carers • outcomes measured by personalised and validated tools such as the 'measure of processes of care' (MPOC) tool, or the 'patient feedback questionnaire' (PFQ) • a reduction in duration and frequency of behaviour that challenges • stability of placements • participation in education by children and young people • reports on the use of restrictive interventions, including medication • contact time with specialist professionals • evidence from quality reviews and spot checking involving experts by experience • quality checks by user-led organisations. 1.1.11 Inpatient services should provide the evidence in recommendation 1.1.10 in addition to evidence of detailed assessments, treatment outcomes and time to discharge. 1.1.12 Commissioners should establish a multi-agency group, including experts by experience and service providers, to monitor the quality of services and the outcomes achieved. 1.1.13 Service providers should use evidence gathered to continuously improve services. They should record the results and make them available to people who use services, and their families and carers. Involving people in commissioning and service improvement Recommendation for commissioners 1.1.14 Commissioners should make use of expertise from experts by experience to inform decision-making and quality assurance of services.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.

Review questions	1.1 What types of community-based services (including residential) are effective and cost effective for people with learning disabilities and behaviour that challenges? 1.3. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different types of community and inpatient services. 1.2. What is the effectiveness of different types of in-patient services (in and out of area) for children, young people and adults with learning disabilities and behaviour that challenges? 1.3. What is the cost effectiveness of different types of services for children, young people and adults with learning disabilities and behaviour that challenges? 2.1. What is the appropriate community-based (including residential care) service capacity for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.1. What models of service delivery are effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.3. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different models of service delivery? 5.1. What mechanisms enable effective joined-up working between education, health and social care service providers supporting children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers?
Quality of evidence	There was little direct research evidence for the effectiveness and cost effectiveness of different types of services and different models of service delivery. In the absence of research evidence that directly answered these questions the review team presented evidence from studies that could report on the current barriers and facilitators to good service delivery. These recommendations on achieving change are the potential solutions to problems and issues identified in the indirect evidence of barriers and facilitators to access, studies of views and experiences, expert witness testimony and the Guideline Committee's experiential and practice based knowledge. To consider appropriate inpatient and community capacity, the review team included studies that might provide some insights in to how the whole system currently works or does not work. The studies included views and experiences studies of the barriers and facilitators identified by professionals and people who use services, process evaluations about implementation and secondary analysis of administrative data providing patterns of service use and to identify potential service needs. They reflect findings from a range of studies, of varying quality and design. The review did not find cost effectiveness evaluation evidence for these recommendations Weaker study designs that included costs were included for consideration to offer insights as the

	potential costs and benefits but were not conclusive. These recommendations are a combination of the research evidence and Guideline Committee expertise. Therefore it was vital that commissioners assure themselves of the quality and specialism of the services that they commission. Recommendation 1.1.9 was based on expert witness testimony DS02. Recommendations 1.1.10 and 1.1.11 were based on 8 evidence statements that related to review questions on effectiveness and cost effectiveness of types of services, views and experience of services, community capacity, models of services delivery and mechanisms of integrated working. Evidence statement ECH6 compared costs and quality of service for in and out of area placements for review question 1.3. Evidence statement AC6 was based on 4 mixed quality studies for review question 2.1. Evidence statement SP8 found evidence on the effectiveness of community forensic service for review question 1.1. this was based on 2 studies of low quality. Evidence statement AC13 found evidence of potential service needs for sexual related behaviour for review question 2.1 and was based on 3 studies: 2 low quality, 1 low moderate quality. Evidence statement SM12 related to respite care and short breaks for children and was based on 2 low quality views and experiences studies, and 1 high quality randomised controlled trial for review question 1.3. Evidence statement SM29 related to one high quality UK randomised controlled trial that the quality of social care impacts on behaviour that challenges for review question 3.1. Evidence statement Int1 about multi-agency working and effective ways of integrating services, this was based on 4 studies, 1 moderate quality and 3 low quality for review question 5.1. The recommendation also drew on High quality Systematic review evidence of 3 studies of people who use services and their families and carers was included for review question 1.3. As there was relatively weak evidence in this area, these recommendations were also based on expert witness testimony of current good practice seen in Transforming Care pilot area programmes (provided by a representative from the Transforming Care Partnership Board and a lead clinical practitioner on the Transforming Care board) evidence statements TC01 and TC02 (1.1.11) and the knowledge of Guideline Committee members. Recommendation 1.1.12 was based on evidence from review question 5.1, using 1 evidence statement Int2 about drawing in expertise from other organisations. This was based on 5 studies, 1 moderate quality and 4 poor quality. This evidence was extrapolated to consideration of quality assurance, drawing on the knowledge of Guideline Committee members. Recommendation 1.1.13 was based on evidence statement SM29 related to one high quality UK randomised controlled trial on the quality of social care impacts on behaviour that challenges for review question 3.1. Recommendation 1.1.14 was based on 1 evidence statement Int1 about multi-agency working and effective ways of integrating

	services, this was based on 4 studies, 1 moderate quality and 3 low quality for review question 5.1.
Economic considerations	The Guideline Committee considered cost effectiveness evidence on in- versus out-of-area placements (recommendation 1.1.13). The evidence suggested that people in out-of-area placements were not receiving appropriate levels of access to professional support and organisations' working practices were not as high as would be expected considering that they were viewed as 'specialist' services and were expected to provide specialist services. The evidence further suggested that in some areas, individuals in out-of-area placements accessed local services rather than being given specialist care through the providing agency. Such findings indicate an inappropriate use of resources; as such investments could have been invested in the person's home area. The Guideline Committee considered this evidence and thought that value for money could potentially be improved through better quality assurance of standards. Recommendations 1.1.10 to 1.1.13 therefore aim to enhance the value for money provided by services via improved quality assurance. In relation to 1.1.14, the committee acknowledged that employing an expert by experience within the commissioning team would have a resource impact. However, the view of the committee was that that this role would lead to more efficient use of resources in terms of ensuring that services met the needs of people with learning disabilities and challenging behaviour.
Evidence statements – numbered evidence statements from which the recommendations were developed	AC6 (recommendation 1.1.10, 1.1.11) AC13 (recommendation 1.1.10, 1.1.11) DS02 (recommendation 1.1.9) ECH6 (recommendation 1.1.10, 1.1.11) Int1 (recommendations 1.1.10, 1.1.11, 1.1.14) Int2 (recommendation 1.1.12) SP8 (recommendation 1.1.10, 1.1.11) SM12 (recommendation 1.1.10, 1.1.11) SM29 (recommendation 1.1.10, 1.1.11, 1.1.13) Systematic review evidence (recommendation 11.1.10, .1.11) TC01 (recommendation 1.1.11) TC02 (recommendation 1.1.11)
Other considerations	Recommendation 1.1.9 was based on expert witness testimony DS02 from a case study of services in Devon (comprising testimony from a commissioner, a provider from a charity that supports people with learning disabilities, and the mother of a young women with learning disabilities who had previously displayed behaviour that challenged services). The commissioner and provider talked about successfully moving people from inpatient settings in to the community. They thought that a contributory factor to their success had been their willingness to take a shared approach to risk, and not relying on risk averse practice and increasing restriction on people. This was supported by the professional experience of Guideline Committee members. Recommendation 1.1.10 was based on

	several evidence statements across different review questions: Evidence statement ECH6 found people in out-of-area placements do not necessarily receive superior services. Evidence statement AC6 found that a lack of local specialist and crisis community services leads to out of area placements. Evidence statement SP8 was about the effectiveness of community forensic services. Evidence statement AC13 was about the prevalence of sexual related behaviour that challenges and potential service needs. Systematic review evidence provided information on the views and experiences of people who use services and their families and carers. Evidence statement SM12 was about short breaks and respite services. Evidence statement SM29 found that better quality social care prevents and reduces behaviour that challenges. The Guideline Committee considered the pressure shifted onto local services and negative outcomes when services do not meet the standards or specialisms necessary to meet the needs of people with complex needs. The view of the committee was that it was important that commissioners were able to quality assure the outcomes that services are achieving. The suggested outcome measures are based on the professional experience of committee members. Reference to using measures of reduction in frequency and duration of behaviour that challenges, participation in education, use of restrictive interventions and quality checks by user-led organisations was added to recommendation 1.1.10 based on GC consensus following stakeholder feedback. Recommendation 1.1.11 was based on the same evidence, but noting additional outcome measures relevant to inpatient settings. The expert witness testimony TC01 and TC02 related to the transforming care programme also emphasised the need to incorporate quality assurance at all levels and to 'measure what you value' and that PHBs, and EHS plans could work as levers to achieve change Recommendation 1.1.12 was based on evidence statement Int2 which related to partnership working and drawing in expertise from different teams. The committee extrapolated this evidence to apply to quality assurance. The view of the committee was that quality assurance of services should be overseen by a multi-agency group, including experts by experience. Recommendation 1.1.13 was also based on evidence statement SM29. This recommendation highlights the responsibility of service providers to engage in continuous improvement activities. Recommendation 1.1.14 was based on 1 evidence statement Int1 on multi-agency working, which was based on 4 studies, 1 moderate quality and 3 low quality. The committee extended the evidence on multi-agency working to include co-production between agencies and people who use services.

Topic/section heading	Involving people and their family members and carers
Recommendations	Involving people with a learning disability and behaviour that challenges Recommendations for practitioners working with children, young people and adults and their families and carers 1.2.1 Practitioners working with children, young people and adults with a learning disability and behaviour that challenges and their family members and carers, should get to know the person they support and find out what they want from their lives, not just what they want from services. For more information on involving people in their care and support, see working with people with a learning disability and behaviour that challenges, and their families and carers in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions. 1.2.2 Actively involve people with a learning disability in all decisions that affect them. If a person aged 16 or over lacks the capacity to make a decision, staff must follow the Mental Capacity Act 2005. 1.2.3 Assess whether a child or young person under the age of 16 is Gillick competent and work in partnership with all children and young people. Include them in decisions about their treatment and ask them how they would like their families or carers to be involved. 1.2.4 Involve families, friends, carers or independent advocates if this is what the person wants, or where decisions are made in the best interests of a person aged over 16 in line with the Mental Capacity Act 2005. This should be done unless there is a compelling reason not to (for example if there are safeguarding concerns). 1.2.5 Support children, young people and adults with a learning disability and behaviour that challenges to live where and how they want. Give them support that: • is person centred, reflecting their individual needs and choices and maximising their control • helps them take an active part in all aspects of daily life that they choose, based both on what they can do and what they want to do • takes into account the severity of their learning disability; their developmental stage; any communication difficulties or physical or mental health problems; and their life history • respects their cultural, religious and sexual identity • helps them before problems occur or as soon as they emerge, not just when crisis has been reached • encourages people to speak out if they have any worries • promotes continuity of relationships. 1.2.6 Find out children, young people and adults' information and communication needs, record them and share this

	information with everyone working with them in line with the Accessible Information Standard. Recommendation for commissioners and practitioners working with children, young people and adults 1.2.7 Ensure that people with a learning disability and behaviour that challenges have access to speech and language therapy when they need it. Advocacy Recommendations for local authorities 1.2.8 Consider providing access to independent advocacy whenever it is wanted or needed by a person with a learning disability and behaviour that challenges. As a minimum it must be offered by local authorities as described in the Care Act 2014, Mental Capacity Act 2005 and Mental Health Act 2007. 1.2.9 Ensure that independent advocates working with children, young people and adults with a learning disability and behaviour that challenges have skills and experience in working with these groups, and in working with specialist learning disability services. See also recommendations 1.8.3 and 1.8.4 on independent advocacy in relation to inpatient admissions.
Research recommendations	What models of delivering person-centred support are effective and cost effective for children, young people and adults with a learning disability and behaviour that challenges, and their families and carers? What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different models of delivering person-centred support?
Review questions	3.3. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different models of services delivery?
Quality of evidence	These recommendations are based on evidence statements for the review questions on people's views and experiences of models of service delivery. The overall quality of the studies was mixed, with three high quality systematic reviews of views and experiences and the remainder from low to high quality. The Guideline Committee also reviewed the recommendations in the aims and principles section of the NICE clinical guideline on Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges which complements this service model guideline. For recommendations 1.2.1 to 1.2.9 the Guideline Committee thought that there was not enough high quality research evidence about the effectiveness and cost effectiveness of different models of delivering person centre support which is why the committee has made a research recommendation in this area. The evidence for recommendations 1.2.1 and 1.2.4 was based on 2 evidence statements. Evidence statement SM15 which was that staff do not always have the right knowledge, skills and qualities to provide good care. This was derived from 5 views and

	experiences studies: 3 studies of moderate quality, 1 study of high quality and 1 high quality systematic review and evidence statement SM17 which was based on 2 moderate quality studies both from review question 3.3 Recommendation 1.2.5 was adapted from the evidence for the recommendations in section 1.3, and the aims and principles in the NICE clinical guideline on Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. The Guideline Committee further developed this recommendation to be focused on how services should be delivered. Evidence for recommendation 1.2.6 was a Guideline Committee consensus recommendation.
Economic considerations	No cost effectiveness evidence was identified for these recommendations. Recommendations 1.2.8 and 1.2.9 could potentially extend eligibility to independent advocates over and above that provided for in legislation. The provision of advocacy to individuals based on need is an investment. If advocacy is effective in representing people's needs and helps people navigate a complex service system, this has the potential to lead to the provision of the right services at the right time which match individuals' needs, which can lead to better outcomes and more efficient use of resources.
Evidence statements – numbered evidence statements from which the recommendations were developed	GC3 systematic review evidence (recommendations 1.2.1, 1.2.4) SM15 (recommendations 1.2.1, 1.2.4, 1.2.7) SM17 (recommendations 1.2.1, 1.2.4)
Other considerations	Recommendations 1.2.1 and 1.2.4 were based on evidence statements from the systematic reviews of the views and experiences of services from family, carers and adults with learning disabilities and behaviour that challenges and evidence statements SM15 and SM17 which found that it was important to support the person and their family in the way that they want. This evidence was supported by the experts by experience on the Guideline Committee. The Guideline Committee discussed the issues around confidentiality, information sharing and safeguarding in relation to involving people's families. Nonetheless, there was agreement that services should work closely with families, involving them in care planning where the person wants their family involved. In addition, the Guideline Committee pointed out that all practitioners should follow the recommendations on support and interventions for family members or carers in the clinical guideline. In relation to recommendation 1.2.1, the Guideline Committee thought that there was not enough high quality research evidence about what the appropriate capacity of different types of community based services needs to be to rebalance care into the community instead of inpatient and closure of inpatient beds as

	part of the Transforming care programme. This is why the committee has made a research recommendation in this area. Recommendations 1.2.2. and 1.2.3 were based on Guideline Committee consensus after discussions of evidence on the importance of involving people in their own care if this is what people want. The Guideline Committee further discussed the importance of involving people in decisions about their own care if they have the capacity to do so, including at such a stage as when children can make decisions about their own care and who they want involved in their care. Recommendation 1.2.5 was based on the recommendations on section 1.3 which was about enabling person-centred care. The Guideline Committee also referred to and adapted the aims and principles section of the NICE clinical guideline on Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges which complements this service model guideline. Recommendation 1.2.5 was thought to be particularly important for 3 groups highlighted through the Equality Impact Assessment: people with different ethnicity, religion or beliefs; people with different degrees of disability; and people with different sexual orientations. Recommendation 1.2.6 was based on discussions by the Guideline Committee that unmet communication needs was a barrier to getting good care. The Guideline Committee found that services should be more proactive in finding out what people needed to know and providing the information they needed in a format best suited for them, and this would include addressing any additional communication needs. The Guideline Committee also referred to the recommendations in the clinical guideline about the communication adaptations recommended in the general principles of care, working with people with a learning disability and behaviour that challenges, and their families and carers. It was also supported by expert witness testimony from the Devon case study that stated that having a working document that outlines what works for the person is important. Recommendation 1.2.7 was based on evidence statement SM15 which was about views and experiences of people, families and carers who said that they found that staff did not have the right skills or knowledge. The Guideline Committee discussed the importance of generalist care staff being able to access specialist staff when they need to and have the skills to recognise when they needed to access specialist staff. The Guideline Committee noted that communication barriers were significant barriers to good care. Recommendations 1.2.8 and 1.2.9 were consensus recommendations following on from discussions about the importance of the availability of advocacy to enable involvement in one's own care and decision making, but also that to be effective, advocates had to have specialist knowledge of navigating services for learning disabilities and behaviour that challenges. The view of the committee was that this could only happen if the commissioner made sure that independent

	advocates could demonstrate they had this specialist knowledge and skills in this area.

Topic/section heading	**Coordinating care and support**
Recommendations	Recommendations for local authorities, clinical commissioning groups and service providers 1.2.10 Local authorities working in partnership with healthcare professionals should assign a single practitioner, for example a social worker (in a disabled children's team or community learning disability team) or community psychiatric nurse, to be the person's 'named worker'. The named worker should get to know the person and coordinate support to meet their needs over the long term. 1.2.11 The local authority, clinical commissioning group and service providers should liaise regularly with the named worker, keeping them informed and involved in decision making. Recommendations for the named worker 1.2.12 Arrange regular meetings to discuss the person's care and support and invite people in their support network, including family members, carers, advocates and practitioners from all services that support them. This could build on existing processes, for example, the education, health and care planning and review process for children (see Gov.uk's children with special educational needs and disabilities). 1.2.13 Recognise and use the expertise brought by all members of the person's support network (not only those who are paid).
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	3.1. What models of service delivery are effective for children, young people, and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.3. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different models of services delivery? 5.2. What mechanisms enable effective joined-up working between health and, social care providers of services and with children, young people, and adults with behaviour that challenges, and their families and carers?
Quality of evidence	The evidence for these recommendations came from the review questions on models of service delivery and mechanisms of joined up working. We did not identify other studies of high quality that compared the effectiveness or cost effectiveness of one model of service delivery over another. In the absence of direct evidence, the review team included studies that might provide some insights in to how the whole system currently works or does not work. The studies included views and experiences about the barriers and

	facilitators identified by people who use services and professionals, and process evaluations about implementation. The evidence on the effectiveness of a named worker is limited but indirect evidence from research on views and experiences and the Guideline Committee's practice and personal experience which strongly suggests that families find the current organisation services complex and difficult to navigate. These recommendations were derived from a combination of research evidence and the Guideline Committee's own expertise. Recommendation 1.2.10 was based on 6 evidence statements, Evidence statement Int8 came from review question 5.2 and found that building services around the person helps to make sure that services work better with the person and their family and was based on 3 low quality studies. Evidence statement SM3 came from evidence from review question 3.1 and said that different people working together was necessary for a care pathway to work. This was based on 3 low quality studies. SM11 from review question 3.3 found that it was difficult finding your way around services which could be a barrier to care and was based on 1 low quality and 1 high quality study. The evidence for SM15 from review question 3.3 found that staff did not always have the right knowledge and skills. This was based on 5 studies: 3 of moderate quality and 2 high quality studies. The evidence for SM17 from review question 3.3 was based on 2 moderate quality studies and found that it was important to work in a way that supports the person and their family. SM33 was about what helps to move people from long stay hospitals to the community and was based on 2 low quality studies. The evidence for what helps to move people from long stay hospitals was limited to the provision of advocacy. Recommendations 1.2.11,1.2.12 and 1.2.13 were derived from evidence statement SM23 which was about the timing of access to support. This was based on 3 moderate quality studies from review questions 3.1 and 3.3. As this evidence did not relate directly to holding meetings, the recommendation also relied on the knowledge of Guideline Committee members.
Economic considerations	No cost-effectiveness evidence relating to the recommendations was identified. However, the Guideline Committee were mindful of the potential resource implications. Recommendations 1.2.10, 1.2.11, 1.2.12 and 1.2.13 are potentially resource intensive activities. However, the use of a 'named coordinator' and the facilitation of regular meetings with the individual's network of friends, family, and carers is an investment which has the potential to improve services' understanding of individuals' needs which could lead to them providing care and services that meet those needs. This could then lead to better outcomes and the more efficient use of resources. It was noted that work to explore similar roles (for example, the named social worker pilot projects) was already taking place nationally.
Evidence statements – numbered evidence	Int8 (recommendation 1.2.10) SM3 (recommendation 1.2.10) SM11 (recommendation 1.2.10)

statements from which the recommendations were developed	SM15 (recommendation 1.2.10) SM17 (recommendation 1.2.10) SM23 (recommendation 1.2.11, 1.2.12, 1.2.13) SM33 (recommendation 1.2.10)
Other considerations	Recommendation 1.2.10 was based on evidence statements Int8, SM3, SM11, SM15, SM17 and SM33. This included evidence on ways to help make service more joined up by building services around the person (Int8), that different people working together was important to making care pathways work well (SM3), people said that it was difficult to find your way around services. Evidence for SM11 related to difficulties families experienced in finding their way around services, which could be a barrier to care. Evidence statement SM17 related to working in ways that support the person and their families particularly in involving them in decision making and being kept informed on a day to day basis. Evidence statement SM15 said that staff did not always have the right knowledge and skills and should work with families as experts. Evidence statement SM33 related to moving from long stay hospitals to the community benefited from the help of an advocate. The Guideline Committee discussed the amount of evidence that suggested overall that people and their families found services difficult to navigate and this was a barrier to care. The committee noted the importance of making the person and their families the centre and having a single named worker as a solution to the issues raised in the evidence statements. This person would be was responsible for helping people navigate the complex services landscape to access the right services at the right time. Recommendations 1.2.11, 1.2.12 and 1.2.13 were based on evidence statement SM23 about how to improve access to services, such as involving families as experts in their own care and facilitating a network of support around the person. The Guideline Committee developed this recommendation further from a discussion on the role of an advocate as coordinator to having a named support worker who would take on the care coordinating and case management role. This also incorporated a previous recommendation that services should support the person to identify friends and family who can support them in this care and support planning process and to access independent advocacy. Reference to building on existing processes such as the Education, Health and Care planning process was added based on GC consensus following stakeholder feedback.

Topic/section heading	**Care and support planning**
Recommendations	Recommendations for community learning disability teams and service providers 1.2.14 Community learning disability teams (or relevant children's services, for example disabled children's teams) and service providers should work in partnership with the child, young person or adult, their family members, carers and advocates and their

	named worker to develop, deliver and review their care and support plan. Develop a care plan that: - meets the person's needs and preferences - works to support and maximise the person’s mental capacity - takes into account people’s fluctuating mental capacity and needs - adopts a ‘whole life’ approach that covers what they want to achieve in both the short and long term and supports smooth transitions - takes a positive approach to managing risk - sets out what to do to prevent or respond to a crisis. 1.2.15 Service providers and agencies responsible for commissioning and planning services (including specialist services) should match the specific skills of staff to the characteristics of the person with a learning disability and behaviour that challenges. Do this as soon as care and support planning begins. 1.2.16 Community learning disability teams or relevant children’s services, (for example disabled children’s teams) and service providers should review children, young people and adults’ care and support with their named worker: - according to timings agreed in their plan and - whenever there is a significant change, for example, if the person is placed out of area. 1.2.17 When reviewing plans: - involve people as set out in recommendations 1.2.1 to 1.2.4 - take account of people’s fluctuating mental capacity - check that staff are following the behaviour support plan recommendations in NICE’s guideline on challenging behaviour and learning disabilities: prevention and interventions - think about plans for the future, including whether changes might be needed to the person’s housing or support. 1.2.18 As soon as a child, young person or adult develops behaviour that challenges, community learning disability teams (or relevant children’s services, for example, child and adolescent mental health learning disability teams) and service providers should offer to work with them and their family or carers to develop a behaviour support plan. For more information on what this should include, see the recommendations on behaviour support plan in NICE’s guideline on challenging behaviour and learning disabilities: prevention and interventions.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	1.1. What is the effectiveness of different types of community based services (including residential) for children, young people

	and adults with learning disabilities and behaviour that challenges? 1.3. What is the cost effectiveness of different types of services for children, young people and adults with learning disabilities and behaviour that challenges? 3.1. What models of service delivery are effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.2. What models of service delivery are cost effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.3. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different models of services delivery?
Quality of evidence	The evidence for these recommendations came from the review questions on models of service delivery and mechanisms of joined up working. We found few studies of high quality that compared the effectiveness or cost effectiveness of one model of service delivery over another or what types of services are effective or cost effective. In the absence of direct evidence, the review team included studies that might provide some insights in to how the whole system currently works or does not work. The studies included views and experiences about the barriers and facilitators identified by people who use services and professionals, and process evaluations about implementation. There was no direct evidence of the effectiveness of the care pathway approach compared to other approaches. However, the Guideline Committee wished to contribute to the existing recommendation in the clinical guidelines to adopt a pathway approach to delivering services. The review team sought studies of a design to answer question on how the pathway might be implemented and work well as part of the models of service delivery review question. The studies included process evaluations, and people’s views and experiences of barriers and facilitator’s to good care in the system of service delivery. These recommendations are derived from a combination of the research evidence and Guideline Committee expertise. Recommendation 1.2.14 was based on 3 evidence statements. Evidence statement SM3 about working together to make care pathways work was provided by 3 low quality evaluation studies from review question 3.1. Evidence statement SM17 on involving families in care planning was provided by 2 moderate quality studies from review question 3.3. Evidence statement SM20 on what helps and does not help services working together related to review question 3.3 and was based on 3 studies: 2 moderate and 1 low quality studies. Recommendation 1.2.15 was based on evidence statement SM24 on staff skills and knowledge, including personal qualities of staff and was provided by 3 moderate quality studies answering review questions 3.1 and 3.3. It was supported by witness expert

	testimony DS03 based on a case study of services in Devon (comprising testimony from a commissioner, a provider from a charity that supports people with learning disabilities, and the mother of a young women with learning disabilities who had previously displayed behaviour that challenged services). Recommendations 1.2.16 and 1.2.17 were adapted from section 1.6 of NICE's guideline on Challenging behaviour and learning disabilities: prevention and interventions and is also based on evidence statement SM3 which came from evidence from review question 3.1 and said that different people working together was necessary for a care pathway to work. This was based on 3 low quality studies. This evidence is also supported by expert testimony DS03 and DS04, based on a case study of services in Devon (comprising testimony from a commissioner, a provider from a charity that supports people with learning disabilities, and the mother of a young women with learning disabilities who had previously displayed behaviour that challenged services). Recommendation 1.2.18 was based on GC consensus. The recommendation cross-refers to the information provided in section 1.6 Behaviour support planning NICE guideline on Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges.
Economic considerations	The review did not find cost effectiveness evidence for this review question. Weaker study designs that included costs were included for consideration to offer insights as the potential costs and benefits but were not sufficiently conclusive to make strong recommendations. The Guideline Committee were mindful of resource impact, in particular in relation to providing families and carers with strategies and interventions to increase communication and other skills to reduce the risk of developing behaviour that challenges. This recommendation therefore cross-refers to the clinical guideline on Challenging behaviour and learning disabilities: prevention and interventions.
Evidence statements – numbered evidence statements from which the recommendations were developed	DS03 (recommendation 1.2.15, 1.2.16, 1.2.17) DS04 (recommendation 1.2.16, 1.2.17) SM3 (recommendation 1.2.14, 1.2.16, 1.2.17) SM17 (recommendation 1.2.14) SM20 (recommendation 1.2.14) SM24 (recommendation 1.2.15)
Other considerations	Recommendation 1.2.14 was based on evidence statement SM17 about involving families; evidence statement SM3, which related to evidence that found that working together is very important to making care pathways work well, and evidence statement SM20 which considered what things worked and did not work so well in services working together. This evidence statement gave care planning as an example of way that can help services work better together. The Guideline Committee considered the evidence on services working together with the person and their families and carers and what this meant for care planning and delivery. They

	discussed the importance of putting a shared approach in place; making sure that the person and their families – or significant people in their lives – are part of the solution and a key source of ideas. The person and their family should have every opportunity to be involved in a variety of different ways and there should be an individualised care approach. Recommendation 1.2.15 was based on evidence statement SM24 which talked about the personal qualities of staff in services that worked well. It also found staff characteristics and behaviour that people did not like, such as over-involvement in staff in their lives that did not match to their needs. The experts by experience in the Guideline Committee said that it was very important to them that staff should get to know the person by developing genuine two-way relationships - rather than operating in a 'robotic' way. It is important not to label people because they have a learning disability and to find out the appropriate level of staffing and kind of support needed to ensure that the level of staff support is not intrusive. This was also supported by the expert witness testimony DS03 from the Devon case study who also suggested that matching the person and their key support workers with similar interests was one of the key things for services and commissioner to get right. Recommendations 1.2.16 and 1.2.17 on regularly reviewing support and planning for the future was based on evidence statement SM3 which looked at how to best implement a care plan which included working with different people from a range of organisations. The recommendation was also adapted from section 1.6 Behaviour support planning in the NICE clinical guideline that accompanies this service guideline - Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. The Guideline Committee also said that the family and other people important to the person should be part of that range of people as experts by experience and a source of ideas and expertise. Although evidence statement SM3 was drawn from working together to make a care pathway work in hospital, the Guideline Committee said this thinking of a care plan should be part of a whole life care pathway, not just when a person is in hospital. The Guideline Committee noted the importance of not viewing challenging behaviour as a diagnosis or a fixed characteristic, that in reality people's needs can fluctuate and planning for care needs to be able to recognise this and response accordingly and when needed. The time when care plans should be reviewed should be as needed, depending on the situation such as a change of care setting or a reduction or increase in behaviour that challenges). The Guideline Committee also considered expert testimony, evidence statements DS03, DS04 from the mother of a young woman with learning disabilities who had in the past displayed behaviour challenged services , a commissioner for learning disability services and an organisation that provides personalised support. They said that working with the person and their family to produce an Individual Service Design (ISD), providing flexible,

	bespoke services could be more cost effective in the long term, as they were able to safely reduce support, creating some savings. It takes time for savings to show up as initially bespoke services appear more expensive than inpatient, but the impact on behaviour that challenges can often be immediate. They said that this model of planning and delivering care needs a long-term view. Recommendation 1.2.18 was based on GC consensus and section 1.6 Behaviour support planning in the NICE clinical guideline that accompanies this service guideline - Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges.

Topic/section heading	**Supporting people to use personal budgets**
Recommendations	Recommendations for local authorities and clinical commissioning groups 1.2.19 Ensure that a range of funding arrangements are available, including direct payments, personal budgets or individual service funds, depending on children, young people and adults' needs and preferences. 1.2.20 Offer people a choice of funding arrangements (see recommendation 1.2.19) and support people to use these budgets, where they wish to, by: • telling them how each element of their support will be funded • telling them how much money is available and how much control they have over how the money is spent • giving them and their families and carers information about different ways of managing their budgets, and how these may affect their carer • supporting them to try out different mechanisms for managing their budget • offering information, advice and support to people who pay for or arrange their own care and support, as well as to those whose care and support is publicly funded • offering information about benefits entitlement • ensuring that carers' needs are taken fully into account. [This recommendation is adapted from NICE's guideline on older people with social care needs and multiple long-term conditions] Delivering care and support Recommendations for staff in all settings 1.2.21 In all settings, staff working with children, young people and adults with a learning disability and their families and carers should aim to reduce the risk of behaviour that challenges developing by:

	• identifying health or sensory problems early • providing strategies and interventions to support communication. Follow recommendations on psychological and environmental interventions in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions. 1.2.22 For people taking medicines: • follow recommendations in NICE's guideline on managing medicines for adults receiving social care in the community and • if the reason for the medicine relates to the person's behaviour or mental health, ensure it is reviewed regularly in line with recommendations on medication in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions, and recommendations in mental health problems in people with learning disabilities: prevention, assessment and management. 1.2.23 Ensure that children, young people and adults with a learning disability and behaviour that challenges know about and are able to use services to support their health and wellbeing. These should include: • services helping people to make and maintain friends, relationships and social networks in their community and take part in community activities • access to employment and pre-employment opportunities • day opportunities where activities can be tailored to the person's interests, preferences, strengths and abilities • universal healthcare services and health checks • peer support opportunities.
Research recommendations	What interventions are effective in supporting families, carers and staff to be resilient and able to provide care and support to people with a learning disability and behaviour that challenges? What models of delivering person-centred support are effective and cost effective for children, young people and adults with a learning disability and behaviour that challenges, and their families and carers? What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different models of delivering person-centred support?
Review questions	3.1. What models of service delivery are effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.2. What models of service delivery are cost effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.3. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that

	challenges, their families and carers of different models of services delivery?
Quality of evidence	The evidence for recommendations 1.2.19 and 1.2.20 came from the review questions on models of service delivery. There were few studies of high quality that compared the effectiveness or cost effectiveness of one model of service delivery over another, including the use of personal budgets that related our specific population. In the absence of direct evidence the Guideline Committee's derived these recommendations from their own expertise, adaptations from recommendations in existing guidelines and expert witness testimony. Recommendation1.2.21 was based on 3 evidence statements. Evidence statement SM13 about access to services for children was provided by 2 studies, 1 low quality and 1 moderate quality from review question 3.3. Evidence statement SM20 on what helps and does not help services working together was based on 3 studies, 2 moderate and 1 low quality studies from review question 3.3. Evidence statement SM23 on the timing of access to support services for children was provided from 3 moderate quality studies from review question 3.1. Recommendation 1.2.22 is adapted from NICE's guidelines on managing medicines for adults receiving social care in the community and section 1.8 Medication of the NICE clinical guideline on Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. Recommendation 1.2.23 was about services to support a person's health and wellbeing and is based on 6 evidence statements: Evidence statement ECU2 from review question 1.1, evidence statements SM21 and SM22 from review questions 3.1, and evidence statement Int12 from review question 5.2. Evidence statement ECU2 is derived from 1 moderate quality UK study. Evidence statement SM21 is derived from 2 UK studies, 1 moderate quality and 1 high quality. Evidence statement SM22 is derived from 2 studies, 1 high quality systematic review and 1 moderate quality study. Evidence statement Int12 is derived from 3 mixed quality studies, 1 moderate quality, and 2 low quality and supported by expert witness evidence statement HPBS05 and TC01.
Economic considerations	There was no cost-effectiveness research relating to these recommendations. Recommendations 1.2.19 and 1.2.20 involve local authorities actively promoting the use of personal budgets and may increase take up and access to services. However, providing the right care and support would lead to better outcomes and more efficient use of resources.
Evidence statements – numbered evidence statements from which the recommendations were developed	Consensus/adapted recommendations. DS05 (recommendation 1.2.20) ECU2 (recommendation 1.2.23) HPBS05 (recommendation 1.2.23) Int12 (recommendation 1.2.23) SM13 (recommendation 1.2.21)

	SM20 (recommendation 1.2.21) SM21 (recommendation 1.2.23) SM22 (recommendation 1.2.23) SM23 (recommendation 1.2.21) TC01 (recommendation 1.2.23)
Other considerations	Recommendation 1.2.19 was based on Guideline Committee consensus in the absence of research evidence for the effectiveness of direct payments, personal health budgets or individual service funds for people with learning disabilities and behaviour that challenges, their families and carers. The Guideline Committee view was that having access to direct payments, personal health budgets or individual service funds was an important part of being able to access person-centred support, as people are able to have some control over what services they can have. In practice the Guideline Committee said that not knowing what personal budgets were available, who was eligible, and what they can be used for was a barrier to people accessing them. Reference to integrated personal commissioning was added based on GC consensus following stakeholder feedback. Recommendation 1.2.20 was adapted from the NICE guideline on older people with social care needs and multiple long-term conditions which recommended that people were supported in the use of personal budgets. The Guideline Committee extrapolated these recommendations for older people and their carers to this population. This was further supported by the expert witness testimony DS05 from the Devon case study which consisted of a commissioner of services, a charity that supports people with learning disabilities accessing services and a mother of a young women with learning disabilities who had displayed behaviour that challenged services in the past. They said that they found that person-centred care included the use of Personal Health Budget (PHB) or by using the PHB as an Individual Service Fund (ISF). This meant they could start with a ‘blank slate’ and not have to compromise too much based on what services there were already available. They said it was a way of people having power and control over their money and life without the overall responsibility which can sometimes involve large sums of money and complicated legal employment responsibilities. Recommendations 1.2.21 were based on evidence statements SM13, SM20, SM23 and Guideline Committee consensus. This included evidence statement SM13 on access to services for children, particularly getting intensive support, and evidence statement SM20 on what helps and does not help services working together. The Guideline Committee noted that people with learning disabilities and behaviour that challenges often do not get help until a long time after they first start having problems. While evidence statement SM20 was about services for children, the Guideline Committee agreed that the same issues applied to adults and the Guideline Committee suggested that early intervention and prevention should apply to children and to adults. This was also the case reviewing the evidence for evidence

	statement SM23 and access to intensive support services for children. The Guideline Committee noted that in their experience children often get help when they are older, even though behaviour that challenges often starts in early childhood. It was the experience of the committee it would help families and their carers if they were skilled in communication and other strategies in early intervention and preventing behaviour that challenges. Links to the relevant part of the clinical guideline were added. Recommendation 1.2.22 was based on GC consensus following stakeholder feedback that there should be reference to services' responsibilities in helping people manage their medicines and prevent over-medication. The recommendation is adapted from the clinical guideline on Challenging behaviour and learning disabilities: prevention and interventions and also NICE’s guidelines on managing medicines for adults receiving social care in the community. Recommendation 1.2.23 was about services to support a person's health and wellbeing is based on 4 evidence statements: ECU2, Int12, SM21 and SM22 and expert witness testimony. The research evidence related to evidence statement ECU2 found that children with more than 1 form of challenging behaviour, and challenging behaviour in the form of aggression or destruction of the environment, use more health-based community services which suggests there is a need for effective and accessible early intervention services. The research evidence related to evidence statements SM21 and SM22 is based on people's views and experiences of services. The evidence suggests that it is important to make sure both people using services and their families stay well and that this does not always happen, for example, sometimes the health of people that go into hospital can get worse. The evidence also suggested that family carers can find it difficult to cope and often feel alone and people can feel lonely even when they are in a place where there are other people, like a group home. Expert witness testimony HPBS05 related to Halton Positive Behaviour Support Service suggested that 'parent burn-out or mental health issues' were one of the main barriers for delivering an effective positive behaviour support service. Expert witness testimony TC01 related to the transforming care programme suggests that annual health checks are helpful levers to enable change and transformation of services. The research evidence related to evidence statement Int12 about the importance of giving the right support at the right time also supports the recommendation in that it suggests when staff undertake regular health checks they should also think about the person’s mental health.

Topic/section heading	**Support for families and carers**
Recommendations	See section 1.6 for more recommendations on services for children and young people.

Recommendations for local authorities

1.3.1 Ensure that families and carers of children, young people and adults with a learning disability and behaviour that challenges are given support that helps them to:

- manage their role as carers
- care for the person and meet their needs, in relation to behaviour, care and support, communication, physical health, mental health, educational needs or any offending behaviour
- access support from specialist services when needed.

1.3.2 Provide information, guidance and ongoing support for families and carers of children, young people and adults with a learning disability and behaviour that challenges which address different aspects of their life. Sources of support could include:

- peer support
- parent and carer groups or forums
- email support
- individual phone and face-to-face support
- family networks
- independent advocacy
- managed email networks (a shared discussion forum)
- social media groups.

1.3.3 Give family members and carers information in line with support and interventions for family members or carers in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions. This could be in the form of a 'welcome pack'. Provide this information:

- at the first point of contact with families
- through the local authority website, local libraries and universal services such as GP surgeries.

Recommendations for the named worker

1.3.4 Help people and their families to understand information about available support (see recommendation 1.3.3) from first contact onwards.

1.3.5 Advise family members and carers how to access:

- short break services
- specialist behaviour support
- training as set out in recommendations 1.7.1 and 1.7.2 in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.
- support in an emergency
- community resources, including voluntary organisations, networks and support groups
- local safeguarding procedures, including how to raise safeguarding concerns or make a complaint.

1.3.6 Ensure that family members and carers have information such as contact details of staff and key dates and appointments.

Research recommendations	What interventions are effective in supporting families, carers and staff to be resilient and able to provide care and support to people with a learning disability and behaviour that challenges?
Review questions	3.1. What models of service delivery are effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.2. What models of service delivery are cost effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.3. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different models of services delivery? 4. What models of service delivery facilitate timely access to effective and cost-effective services for children, young people and adults with learning disabilities and behaviour that challenges 5.2. What mechanisms enable effective joined-up working between health and, social care providers of services and with children, young people and adults with behaviour that challenges, and their families and carers?
Quality of evidence	The evidence for these recommendations came from the review questions on models of service delivery and integration. We found few studies of high quality that compared the effectiveness or cost effectiveness of one model of service delivery over another. In the absence of direct evidence, the review team included studies that might provide some insights in to how the whole system currently works or does not work. The studies included views and experiences about the barriers and facilitators identified by people who use services and professionals, process evaluations about implementation and evidence of best practice from an expert witness for models of service delivery. The evidence on the effectiveness of a named worker is limited but indirect evidence from research on views and experiences and the Guideline Committee's practice and personal experience strongly suggest that families found the system, of services complex and difficult to navigate. Evidence for mechanisms for joint working between services and between people and their families reflect findings from a range of studies, of varying quality and design. Study quality is mixed given the different types of included study designs for this review question and recommendations are based on a combination of research and Guideline Committee's experiential and practice based knowledge. Recommendation 1.3.1 was based on 1 evidence statement SM13 from review question 4 about access to services for children, which is derived from 2 low quality UK studies. As there was relatively sparse evidence in this area, this recommendation also relied on expert witness testimony HPBS01 from Halton Borough Council, which provides a Positive Behavioural Support Service, and the knowledge of the Guideline Committee.

	Recommendation 1.3.2 was based on 3 evidence statements: SM10 SM30 and SM31 from review question 3.1. Evidence statement SM10 is derived from 2 studies, 1 low quality Canadian study and 1 high quality UK study. Evidence statement SM30 is derived from 1 high quality RCT study. Evidence statement SM31 is derived from 1 moderate quality study. Recommendation 1.3.3 was based on 5 evidence statements: SM10 and SM17 from review question 3.3, SM36 from review question 3.1, Int9 from review question 5.2, and AC2 from review question 4. Evidence statement SM10 is derived from 2 studies, 1 low quality Canadian study and 1 high quality UK study. Evidence statement SM17 is derived from 2 moderate quality UK studies. Evidence statement SM36 is derived from 3 low quality studies and comes from review question 3.1. Evidence statement Int9 is derived from 3 mixed quality studies, 2 moderate quality and 1 low quality and comes from review question 5.2. Evidence statement AC2 is derived from 3 mixed quality studies, 2 high quality and 1 moderate quality from review question 4. Recommendations 1.3.4, 1.3.5 and 1.3.6 were based on the 5 same evidence statements (SM10, SM17, SM36, Int9, AC2) as recommendation 1.3.4. Recommendations 1.3.4, 1.3.5 and 1.3.6 were based on 9 evidence statements (SM10, SM17, SM36, Int9, AC2, and SM14, SM23, and SM28 from review question 3.1 , and EcAC4 from review question 4.) Evidence statement SM14 is derived from 2 moderate quality UK studies. Evidence statement SM23 is derived from 3 moderate quality studies. Evidence statement SM28 is derived from 2 UK studies of mixed quality, 1 moderate and 1 low quality. Evidence statement EcAC4 is derived from 1 moderate quality study. Evidence statement SM14 is derived from 2 moderate quality UK studies
Economic considerations	The review did not find cost effectiveness evidence for this review question. Weaker study designs that included costs were included for consideration to offer insights as the potential costs and benefits of different models of service delivery, but were not conclusive. The Guideline Committee were mindful of the resource implications of these recommendations, particularly in terms of specialist services supporting families (recommendation 1.3.1). It was noted that this is already happening in some areas of the country, as shown by the expert witness testimony from Halton Borough Council. It was the view of the committee that adequately supporting families in their role had the potential to lead to cost savings by preventing people (particularly children) from having to enter expensive residential placements. The committee were also mindful of the resource implications of the provision of information. However, they noted that local areas are already required to give information about local provision via the Local Offer, which is a requirement of the Children and Families Act 2014, so significant additional investment should not be required.
Evidence statements – numbered	AC2 (recommendation 1.3.3, 1.3.4, 1.3.5, 1.3.6) EcAC4 (recommendation 1.3.5)

evidence statements from which the recommendations were developed	HPBS01 (recommendation 1.3.1) Int9 (recommendation 1.3.3, 1.3.4, 1.3.5, 1.3.6) SM10 (recommendation 1.3.2, 1.3.3, 1.3.4, 1.3.5, 1.3.6) SM13 (recommendation 1.3.1) SM14 (recommendation 1.3.5) SM17 (recommendation 1.3.3, 1.3.4, 1.3.5, 1.3.6) SM23 (recommendation 1.3.5) SM28 (recommendation 1.3.5) SM30 (recommendation 1.3.2) SM31 (recommendation 1.3.2) SM36 (recommendation 1.3.3, 1.3.4, 1.3.5, 1.3.6)
Other considerations	Recommendation 1.3.1 was about access to services for children is based on 1 evidence statement SM13. The evidence found that people often don't get specialist help for their child until they are older and sometimes 'diagnostic criteria' to do with a child's health were being used to say whether they could use a service or not. The Guideline Committee discussed the importance of providing the right support and investing in families and carers as valued partners and to help people, particularly children and young people, to stay with their families. The view of the committee was that providing the right support to families could stop behaviour that challenges from developing or worsening. This was also supported by the expert witness testimony HPBS01 from Halton Borough Council, who said that part of the role of their Positive Behaviour Support Service was to support families. The Guideline Committee said that families and carers should have access to the same types of professional support that people living in residential care would have access to. Recommendation 1.3.2 was about different forms of support for families and carers is based on 3 evidence statements: SM10, SM30, and SM31. The evidence related to SM10 was about the barriers and facilitators to keep a normal family life going. The evidence related to SM30 found that better quality social care increases staff satisfaction and the evidence related to SM31 found that for people moving out of long stay hospitals into the community, this increases family contact over time. The committee thought that based on their practice and experience that a range of support options should be made available to meets the varied needs of families and parents such as respite, outreach and behavioural advice and that support should be provided by range of health and social care services Recommendation 1.3.3 was about providing information to family members and carers is based on 5 evidence statements: SM10, SM17, SM36, Int9, and AC2. The evidence related to SM10 was about the barriers and facilitators to keep a normal family life going. Evidence statement SM17 related to working in ways that support the person and their families particularly in involving them in decision making and being kept informed on a day to day basis. Evidence statement SM36 related to providing support to families in the home so help prevent residential placements from breaking down. Int9 found that it was important to have regular

	reviews and to involve experts by experience in reviews, and people’s wider social networks. Evidence statement AC2 related to the support needs for families and found that parents of children with moderate ID or physical problems especially needed: respite care, activities for the child and practical/material help. The Guideline Committee discussed the various ways that practical information could be made available to families and carers. The information should include what services there were available to support families, such as short breaks, activities for children and practical help, This would be needed by families at first contact and could take the form of a 'welcome pack'. The Guideline committee also thought that it was important that this information should be widely available for people that might not yet be in contact with services. This 'welcome pack' should be available to access in other places, like libraries and GP surgeries. Recommendations 1.3.4, 13.5 and 1.3.6 was about the responsibilities of the named worker in providing information and support is based on the 5 same evidence statements (SM10, SM17, SM36, Int9, AC2) as recommendation 1.3.4. The research evidence related to family’s needs for practical information and information about navigating services. The Guideline Committee favoured a more engaged approach of providing information, advice and guidance. The Guideline Committee thought that the 'named worker' should play more of a co-ordinating all aspects of support role, rather than simple provider of information. The committee discussed the need to engage with families and not only offer help or information once, but be tuned into the fact that families might need different advice or help depending on their current situation. The part of this recommendation about information and training to families and foster carers is based on 4 evidence statements: SM14, SM23 and SM28. It also cross-references the relevant recommendation in NICE’s guideline on Challenging behaviour and learning disabilities: prevention and interventions. This recommends that families and foster carers should be given training interventions to support them in their role. The evidence related to SM14 was from 1 high quality review that was uncertain about whether increasing the frequency and intensity of intensive community support services decreases behavioural problems. However, the evidence related to SM23 and SM28 found that the timing of support was crucial and needed to be available at home when a crisis occurred in order to prevent a placement from breaking down. The evidence related to EcAC4 suggested that adolescents transitioning to adult services place a large burden on families and carers. 70% of people in one study lived in the parental home and 66% of the total costs of care comprised informal care. The Guideline Committee thought it was extremely important that families and the main people providing support for the person should be trained to be able to support the implementation of behavioural support plans and thought that specialist staff that know their child are best placed to provide this support.

Topic/section heading	**Developing services in the community**

Recommendations	Recommendations for the lead commissioner (acting on behalf of local authorities and clinical commissioning groups)
	1.4.1 The lead commissioner should commission services in the community for people with a learning disability and behaviour that challenges (including for people in contact with, or at risk of contact with, the criminal justice system). These services:
	• should be able to cater for lower-level needs up to intensive, complex or fluctuating needs
	• could be set up either as 1 large team with different subteams or as several separate teams
	• should be provided wherever possible as an alternative to, and to reduce the potential need for:
	  o inpatient care for children, young people and adults or
	  o residential placements for children and young people.
	1.4.2 Services in the community should fulfil the following core functions:
	• specialist prevention and early intervention
	• developing capacity in non-specialist community services to prevent unnecessary inpatient admissions
	• giving support and training to families and carers (by following the recommendations on support and interventions for family members or carers in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions)
	• quality assurance and service development
	• short-term assessment and intervention
	• longer-term complex intervention
	• crisis response and intervention.
	1.4.3 Ensure that children, young people and adults with a learning disability can get specialist support through their community learning disability team that meets their needs, for example in relation to:
	• behaviour
	• communication
	• social care and support needs
	• physical health
	• mental health
	• education
	• offending behaviour.
	This could be achieved by employing relevant practitioners within the community learning disability team or by developing close links with practitioners in other relevant services.

	Recommendations for community learning disability teams and service providers 1.4.4 Services who provide support through the community learning disability team should work together and provide consultancy and support to each other. They should work with children, young people and adults and their family members and carers in a way that is: - personalised - flexible - responsive - accessible - reflective. 1.4.5 If a child, young person or adult develops, or is at risk of developing, offending behaviour, community learning disability teams should refer them to appropriate specialists, such as community forensic or youth justice services, as soon as possible (see recommendations 1.4.12 to 1.4.16). These services should: - provide evidence-based early interventions that are adapted for people with a learning disability and address the specific behaviour - work in an ongoing partnership with each other and with the community learning disability team whenever needed. 1.4.6 Community learning disability teams should maintain good communication and links with the police and liaison and diversion teams so that: - they can advise on assessments of vulnerability, particularly for people with mild or borderline learning disabilities who may otherwise not be identified as vulnerable - people who need support can be diverted from the criminal justice service to community learning disability teams.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	2.1. What is the appropriate community-based (including residential care) service capacity for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.1. What models of service delivery are effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 5.1. What mechanisms enable effective joined-up working between education, health and social care service providers supporting children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 5.2. What mechanisms enable effective joined-up working between health and, social care providers of services and with children, young people and adults with behaviour that challenges, and their families and carers?

Quality of evidence	The evidence for these recommendations came from the review questions on community service capacity and models of service delivery. There was little direct research evidence about the appropriate service capacity for community services or models of service delivery. In the absence of research evidence that directly answered these questions the review team presented evidence from studies that examined characteristics of service use, people's views and experiences to barriers and facilitators to access and take up of services, and studies that reported on potentially negative outcomes such as out of area placements or delayed discharges associated with lack of provision of community services. These recommendations are underpinned by a combination of different study designs. Study quality is mixed given the different types of included study designs for this review question. Evidence for mechanisms of integration complements the clinical guideline's recommendation that services should be integrated. The evidence base included a range of study designs that describe what helps and what does not help service work together and with families. Recommendation 1.4.1 was based on 4 evidence statements from review question 2.1. Evidence on the lack of local specialist and crisis community services, evidence statement AC6 was based on 4 studies, 2 moderate quality and 2 low quality. Evidence on integration of specialist and general service, evidence statement AC11 was provided by 4 studies, 1 moderate quality and 3 low quality. Evidence on community based forensic services, evidence statement AC14 was provided by 1 moderate quality study. Evidence statement AC19 on delayed discharge was provided by 3 studies, 1 moderate quality and 2 low quality. Recommendation 1.4.1 was also based on 2 evidence statements, Int2 and Int4 from review question 5.1. Evidence statement Int2 on drawing in expertise from other organisations, is derived from 5 studies, 1 moderate quality and 4 poor quality. Evidence statement Int4 is derived from 5 UK studies of mixed quality. Recommendation 1.4.2 was based on 5 evidence statements. Evidence statement SM23 on timeliness of access to support was based on 3 moderate quality studies from review question 3.1. This recommendation was also supported by evidence statements AC6, AC11, AC14 and AC19 from review question 2.1 described above. Recommendation 1.4.3 about access to specialist support is based on 3 evidence statements: AC11, Int2 and Int4. Evidence statement AC11 is derived from 3 low quality and 1 moderate quality studies for review question 2.1. Evidence statement Int2 is derived from 5 UK studies of mixed quality and evidence statement Int4 is derived from 5 studies of low overall quality. Recommendation 1.4.4 about integrating practitioners is based on 3 evidence statements: Int2, Int5 and Int12. Evidence statement Int2 is derived from 5 UK studies of mixed quality for review question 5.1. Evidence statement Int5 is derived from 4 UK studies of low overall quality for review question 5.1 and evidence

	statement Int12 is derived from 3 UK studies, including 2 low quality from review question 5.2. Recommendation 1.4.5 about timely referral to specialists is based on 2 evidence statements AC12 and AC13. Evidence statement AC12 about characteristics of offending behaviour and is derived from 2 moderate quality studies from review question 2.1. Evidence statement AC13 about prevalence of sexual related behaviour and is derived from 3 studies, 2 low quality and 1 moderate quality from review question 2.1. Recommendation 1.4.6 about maintaining good links with the criminal justice system is based on the same evidence statements (AC12, AC13) as recommendation 1.4.5.
Economic considerations	The cost effectiveness evidence, evidence statement ECU4 identified that was relevant to 1.4.1 and 1.4.2 suggested the range of services that should be in the community are potentially resource-intensive. However increasing capacity of community based services as an alternative to inpatient services is a key part of the Transforming Care agenda and so local authorities should already be undertaking these changes as part of implementing this agenda. Increasing access to services is likely to have some resource impact, and investment in areas where there is no current provision, but it was the Guideline Committee view based on practice and experience that early intervention and access to general and specialist services when needed is likely to support families and carers to care for the person at home, prevent episodes of crisis and prevent the use of intensive services and out of area and residential placements due to the lack of locally provided services and makes savings over the longer term These recommendations were aligned with the Transforming Care service model in regard to people should have access to a range of service and across services according to need. Community learning disability teams should be multi-disciplinary and support access to mainstream and specialist services and built around the needs of the individual. Services should therefore be developing in this way to meet the requirements of the Transforming Care agenda.
Evidence statements – numbered evidence statements from which the recommendations were developed	AC6 (recommendations 1.4.1, 1.4.2) AC11 (recommendation 1.4.1, 1.4.2, 1.4.3) AC12 (recommendation 1.4.5, 1.4.6) AC13 (recommendation 1.4.5, 1.4.6) AC14 (recommendations 1.4.1 , 1.4.2) AC19 (recommendations 1.4.1 , 1.4.2) ECU4 (recommendation 1.4.1, 1.4.2) Int2 (recommendation 1.4.1, 1.4.3, 1.4.4) Int4 (recommendation 1.4.1, 1.4.3) Int5 (recommendation 1.4.4) Int12 (recommendation 1.4.4) SM23 (recommendation 1.4.2)

Other considerations	Recommendation 1.4.1 is supported by evidence statement AC6 relating to lack of local specialist and crisis community services, evidence statement AC11 about integration of specialist and general services in the community. Evidence statement AC14 about the role of community forensic services and evidence statement AC19 about the lack of community provision leading to delayed discharges. Recommendation 1.4.1 is further supported by evidence statements Int2 and Int4 about integrating practitioners who provide support in teams (Int2) and what helps services or teams work together in a 'joined up' way (Int4). The view of the committee was that local areas should provide a range of community-based support for people with learning disability and behaviour that challenges, catering for a range of needs. There was no strong evidence about how these services should be configured in terms of whether a single integrated team, or a number of teams that worked closely together. The view of the committee was that it was more important that the various functions were covered, and less important how this was configured. The committee thought that different local areas may choose to configure teams differently. The view of the committee was that building up the correct community capacity was a key way to reduce the need for inpatient admissions, or residential placements for children and young people. The committee acknowledged that this was likely to have resource implications in a number of areas where the full spectrum of services may not yet exist. However, it was noted that the recommended approach was similar to that outlined in the Transforming Care model service specifications, and so local areas should be working towards remodelling their services in this way. This recommendation also addressed the needs of people in contact with the criminal justice system and with different degrees of disability (2 groups highlighted through the Equality Impact Assessment). Recommendation 1.4.2 was based on evidence statement SM23 about the importance of having access to services when needed (for example, out of hours). It is also supported by the evidence for 1.4.1 above. As noted above, the view of the committee was that it was not important to specify the configuration of the teams recommended in 1.4.1 but rather the various functions they needed to fulfil. The evidence reviewed suggested for services ranging from early intervention and prevention, specialist support for people with behaviour that challenges, and rapid response support in a crisis. The view of the committee was that this team or set of teams would also be best placed to support families and frontline staff, and cross-referenced the training and support recommended in the NICE guideline on challenging behaviour and learning disabilities: prevention and interventions. As above, the committee acknowledged that this was likely to have resource implications in a number of areas where the full spectrum of services may not yet exist. However, it was noted that the recommended approach was similar to that outlined in the Transforming Care model service specifications, and so local areas should be working towards remodelling their services in this way.

	Recommendation 1.4.3 was based on evidence statements AC11, Int2 and Int4. This included evidence statement AC11 about the need for people with learning disability and behaviour that challenges to be able to access specialist service integrated with general services. It also included evidence statement Int2 that found being able to draw in expertise from outside their own organisation and making links between different sectors was important. Evidence statement Int4 was about what helps services work together in a 'joined up' way. The committee discussed the types and range of specialist expertise that needs to be available to people in the community. Recommendation 1.4.4 was based on evidence statements Int2, Int5 and Int12 which related to how services integrate and work together. This included evidence statement Int2 about integrating practitioners who provide support through the community learning disability team . Evidence statement Int5 about defining how they work, which includes being clear about the roles and responsibilities of different service so that they can work better together. And evidence statement Int12 about the importance of giving the right support at the right time to people so that their problems don't get worse. The view of the committee was that it was important that practitioners and services work in a way that is personalised, flexible, responsive and accessible to people and their family members and carers. Reference to reflective practice was added. Recommendations 1.4.5 and 1.4.6 were based on evidence statements AC12 and AC13 that related to the prevalence of behaviours that challenge that might be described as sexually risky behaviours or behaviours that can be construed as offending, or anti-social. The studies measured prevalence in different ways so it was not possible to arrive at a consensus percentage of the prevalence of these types of behaviours in the population of people with learning disabilities, however the evidence suggests that it is a significant number. The evidence also suggested that to address the needs of this group CLDTs would need to maintain good communication and links with police and liaison and diversion teams and to refer people to appropriate specialists, such as community forensic teams, as soon as possible if risky or offending behaviour are displayed. This group of recommendations also addressed specifically the needs of people in contact with the criminal justice system (a group highlighted through the Equality Impact Assessment).

Topic/section heading	**Specialist behavioural support**
Recommendations	Recommendations for the lead commissioner (acting on behalf of local authorities and clinical commissioning groups) 1.4.7 Ensure that specialist assessment and behavioural support are available in the community so that children, young people and adults can stay where they currently live and avoid moving.

	1.4.8 Ensure that specialist services for behaviour that challenges are available to everyone with a learning disability and behaviour that challenges, based on an assessment of each person's need and risk and taking into account the benefit of early intervention. 1.4.9 The lead commissioner should: • set local maximum waiting times for initial assessment, and for urgent and routine access to treatment and support • ensure that waiting times for specialist behavioural support do not exceed NHS waiting time standards. Intensive behavioural support during a crisis Recommendations for local authorities, clinical commissioning groups, community learning disability teams and specialist services 1.4.10 Provide a local, personalised response to children, young people and adults who need intensive support during a crisis. This response should: • focus on keeping people in their own home • have an out-of-hours helpline as a first option with the capacity to respond rapidly (within 1 hour or in line with local mental health crisis response times), staffed by people with skills and knowledge in learning disabilities and behaviour that challenges, and specialist skills in mental health problems • provide face-to-face support within 4 hours if needed, based on initial triage • involve partnership with other commissioners, service providers and family members and carers • include giving staff access to the person's information if they are already in contact with services • provide short-term support to achieve aims that are agreed with the person • include clear contact details for children's services (as set out in the Local Offer) and adults' services. 1.4.11 Use a clear, coordinated approach to reducing the level of support from more intensive services in line with the person's needs. Learn from what happened and use this knowledge to inform future early intervention and prevention services and support crisis plans.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	2.1. What is the appropriate community-based (including residential care) service capacity for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.1. What models of service delivery are effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers?

	5.1. What mechanisms enable effective joined-up working between education, health and social care service providers supporting children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers?
Quality of evidence	The evidence for these recommendations came from the review questions on appropriate community service capacity and models of service delivery. There was little direct research evidence about the appropriate service capacity for community services or models of service delivery. In the absence of research evidence that directly answered these questions the review team presented evidence from studies that examined characteristics of service use, people's experiences of barriers and facilitators to access and take up of services and studies that reported on potentially negative outcomes such as out of area placements or delayed discharges associated with lack of provision of community services. These recommendations are underpinned by a combination of different study designs. Study quality is mixed given the different types of included study designs for this review question. An expert witness was also invited to provide testimony on community services, which has contributed to these recommendations. Evidence for mechanisms of integration compliments the clinical guideline's recommendation that services should be integrated, and include a range of study designs that describe what helps and what does not help service work together and with families. Recommendations 1.4.7 was based on providing specialist assessment and behavioural support in the community is based on evidence statements: AC9 on shared commissioning for local services derived from 4 low quality studies from review question 2.1, and SM14, based on 1 high quality systematic review from review question 3.1. This was supported by expert witness testimony from Halton Borough Council, which provides a Positive Behaviour Support service in evidence statement HPBS02. Recommendations 1.4.8 and 1.4.9 were based on how specialist behavioural support should be provided is based on 2 evidence statements: AC10 and Int4. Evidence statement AC10 was derived from 4 studies of mixed quality, 3 studies of low quality and 1 study of moderate quality from review question 2.1. Evidence statement Int4 was derived from 4 studies of mixed quality, 2 studies of low quality and 2 studies of moderate quality from review question 5.1. Recommendation 1.4.10 was based on provision of crisis support is based on 5 evidence statements. Evidence statement SM14 was derived from 1 high quality systematic review from review question 3.1. Evidence statement SM23 was derived from 3 moderate quality studies from review question 3.1. Evidence statement SM28 was derived from 2 UK studies of mixed quality, 1 low quality and one moderate quality from review question 3.1. This was supported by expert witness testimony HPBS03 from Halton Borough Council, which provides a Positive Behaviour Support service from evidence statement.. Evidence statement

	EcAC4 was economic evidence derived from 1 moderate quality study for review question 2.1. Recommendation 1.4.11 was based on reducing the level of support is based on 1 evidence statement AC10 derived from 4 studies of mixed quality, 3 studies of low quality and 1 study of moderate quality from review question 2.1. This was supported by expert witness testimony HPBS04 from Halton Borough Council, which provides a Positive Behaviour Support service.
Economic considerations	There was limited cost-effectiveness research relating to these recommendations. However, the Guideline Committee were mindful of the potential resource impact of these recommendations, particularly in areas where services of the kind described do not yet exist. However, it was noted that the recommendations were aligned with the Transforming Care service model (recommendations 1.4.7 to 1.4.9 relate to section 7.1 and 7.2 of Transforming Care; recommendations 1.4.10 and 1.4.11 relate to section 7.3 of Transforming Care about 24/7 multi-disciplinary crisis support). Services should therefore be developing in this way to meet the requirements of the Transforming Care agenda. For recommendation 1.4.10, the Committee thought that being able to deliver in partnership with other similar services (for example out of hours mental health services) could also help to minimise the resource impact for local areas. Following stakeholder feedback, the Committee amended the recommendation to make clearer that the initial response could be by telephone within 1 hour, and would involve triage and assessment to ascertain whether face to face support within 4 hours was necessary. The 1 hour telephone response time and 4 hours responses time after initial triage and assessment is line with NHS England 5 Year Forward plan for Adult Mental Health Crisis and Acute Care. The Guideline Committee extrapolated from this and the research evidence that a 24/7 community response was both feasible and necessary for both adults and children and young people, and in line with guidance on current and future good practice.
Evidence statements – numbered evidence statements from which the recommendations were developed	AC9 (recommendation 1.4.7) AC10 (recommendation 1.4.8, 1.4.9, 1.4.10) ECU4 (recommendation 1.4.10) Int4 (recommendation 1.4.8 and 1.4.9) HPBS02 (recommendation 1.4.7) HPBS03 (recommendation 1.4.10) HPBS04 (recommendation 1.4.11) SM14 (recommendation 1.4.7, 1.4.10) SM23 (recommendation 1.4.10) SM28 (recommendation 1.4.10)
Other considerations	Recommendation 1.4.7 was based on evidence statement AC9 which was about shared commissioning for services being more effective in meeting needs for people locally. The evidence suggested that neighbouring authorities with similar clients could work together to provide an affordable shared specialist

	assessment and behavioural support service. This was supported by the evidence in SM14 that suggested that input from specialist behaviour support was more effective that more frequent visits, outreach teams or smaller caseloads. The committee also took in to account expert witness testimony HPBS02 from a manager of a Positive Behaviour Support Service (PBSS), relating to an existing successful community behavioural support service. Recommendations 1.4.8 and 1.4.9 were based on evidence statements AC10 and Int4 which were about the people most at risk of out of area placements and linking health and social care. The evidence related to evidence statement AC10 found that people from a wide range of groups were at more risk of being placed out of area, especially younger people and people that had more complex support needs. The committee took the view that specialist support should therefore be available to all people with learning disabilities and behaviour that challenges, based on individual need. The '18 weeks to treatment' part of the recommendation is in line with NHS referral to treatment guidelines. The evidence related to Int4 found that making links between different sectors helps services work together in a 'joined up' way. The committee took the view that it was important to have a single lead commissioner that could link health and social care to enable access to specialist services. Recommendation 1.4.10 was based on evidence statements SM14, SM23, and SM28 and related to the provision of intensive support during a crisis. The evidence related to SM14 was from 1 high quality review that was uncertain about whether increasing the frequency and intensity of intensive community support services decreases behavioural problems. However, the evidence from evidence statements SM23 and SM28 found that the timing of support was crucial and needed to be available at home when a crisis occurred in order to prevent a placement from breaking down. This was also supported by evidence statement ECU4 which found that providing a specialist behaviour therapy team plus standard care compared to standard care alone was effective in improving levels of behaviour that challenges. The Guideline Committee developed this evidence further based on their practice and experience to include the essential components for providing a personalised response for people needing access to intensive support. The expert witness testimony HPBS03 from a manager of a Positive Behaviour Support Service (PBSS), highlighted the need to provide a personalised experience and emphasised the need to provide an out of service hours support and to work directly with families, carers and staff to put strategies in place and work across all settings including home, school, short break, outreach, day services. Following stakeholder feedback, the Committee amended the recommendation to make clearer that initial response could be by telephone, and would involve triage and assessment to ascertain whether face to face support was necessary. The 1 hour telephone response time and 4 hours responses time after initial triage and assessment is line with NHS England 5 Year Forward plan for Adult Mental Health Crisis and Acute Care. The Guideline Committee extrapolated from this and the research evidence that a 24/7 community

	response was feasible and necessary for both adults and children and young people, and in line with guidance on current and future good practice. Recommendation 1.4.11 was based on evidence statement AC10 which was about people with learning disabilities and behaviour that challenges most at risk of out of area placements. The evidence found that people from a wide range of groups were at more risk of being placed out of area, especially people that had more complex support needs. The view of the committee was that to help ensure that people are continued to be supported locally it was important that reducing the level of support from more intensive services be in line with the person's needs. The expert witness testimony from a manager of a Positive Behaviour Support Service (PBSS), also highlighted the need to put in place robust maintenance and discharge procedures, to prevent 'procedural drift', meaning to make sure that the procedures or specific strategies put in place for a person continue to be implemented, if they are in line with the person's needs, once they have left the care of an intensive support service. The expert witness testimony HPBS04 from the Devon case study also strongly supported the need to enable a continuing approach and not to take away a specific package, if it was working for the person when they leave the care of an intensive service.

Topic/section heading	**Services for people in contact with, or at risk of contact with, the criminal justice system**
Recommendations	Recommendation for local authorities and clinical commissioning groups 1.4.12 Commission local community forensic services for children, young people and adults with a learning disability and behaviour that challenges who are in contact with, or at risk of contact with, the criminal justice system to prevent out-of-area hospital placement. These could be provided as stand-alone teams, or as a specialism within an existing team, for example a community learning disability team, or a learning disability specialism within a community forensic team. Recommendations for service providers, including forensic services 1.4.13 When forensic community learning disability services are supporting children, young people and adults with a learning disability (for example, if they are subject to a forensic community rehabilitation order or a community treatment order) they should enable them to live in the community, as close to home as possible, and in the least restrictive setting. 1.4.14 Forensic community learning disability services should stay in frequent contact with the person they are supporting, including those who are in out-of-area placements or criminal justice settings, and help them build and maintain social links in their community. 1.4.15 Forensic learning disability services and probation services should work together to agree who is best able to

	support the person in meeting the requirements of their treatment or rehabilitation order. 1.4.16 Forensic learning disability services, mental health, specialist voluntary sector organisations, learning disability services and social care services should establish care pathways and close links with each other to help them refer people quickly between these services to get the right support and effectively manage risk.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	1.1. What is the effectiveness of different types of community based services (including residential) for children, young people and adults with learning disabilities and behaviour that challenges? 1.4. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different types of community and in patient services? 2.1. What is the appropriate community-based (including residential care) service capacity for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 5.1. What mechanisms enable effective joined-up working between education, health and social care service providers supporting children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers?
Quality of evidence	The evidence for these recommendations came from the review questions on appropriate community service capacity, types of services, and models of service delivery. There was little direct research evidence about the appropriate service capacity for community services or types services compared to other types or no service, or models of service delivery. In the absence of research evidence that directly answered these questions the review team presented evidence from studies that could report on the findings that examined characteristics of service use, people's views and experiences to barriers and facilitators to access and take up of services and studies that reported on potentially negative outcomes such as out of area placements or delayed discharges associated with lack of provision of community services. These recommendations are underpinned by a combination of different study designs. Study quality is mixed given the different types of included study designs for this review question Recommendation 1.4.12 on commissioning local forensic services is based on 2 evidence statements AC6 from review question 2.1 and SP8 from review question 1.2. Evidence statement AC6 was derived from 4 studies of mixed quality, 2 studies of low quality and 2 studies of moderate quality. Evidence statement SP8 was derived from 2 studies of mixed quality, 1 study of low quality and 1 study of moderate quality.

	Recommendation 1.4.13 on supporting people with forensic needs is based on 2 evidence statements SP8 and SP9. Evidence statement SP8 was derived from 2 studies of mixed quality, 1 study of low quality and 1 study of moderate quality. Evidence statement SP9 was derived from 1 moderate quality study from review question 1.4. Recommendation 1.4.14 on staying in contact is based on 1 evidence statement SP9 derived from 1 moderate quality study from review question 1.4. Recommendation 1.4.15 on services working together is based on 2 evidence statements SP9 from review question 1.4 and Int3 from review question 5.1. Evidence statement SP9 was derived from 1 moderate quality study and evidence statement Int3 was derived from 1 study of low quality. Recommendation 1.4.16 on referral between services is based on 2 evidence statements SP8 from review question 1.2 and Int4 from review question 5.1. Evidence statement SP8 was derived from 2 studies of mixed quality, 1 study of low quality and 1 study of moderate quality. And evidence statement Int4 was derived from 5 studies of mixed quality, 2 studies of low quality and 3 studies of moderate quality.
Economic considerations	No cost-effectiveness evidence was identified for these recommendations. Stakeholder feedback identified that many areas do not have stand-alone community forensic teams. The recommendation was therefore amended based on GC consensus to state that community forensic support could be provided as stand-alone teams, or as a specialism within an existing team, for example a community learning disability team, or a learning disability specialism within a community forensic team.
Evidence statements – numbered evidence statements from which the recommendations were developed	AC6 (recommendation 1.4.12) Int3 (recommendation 1.4.15) Int4 (recommendation 1.4.16) SP8 (recommendation 1.4.12, 1.4.13, 1.4.16) SP9 (recommendation 1.4.13, 1.4.14, 1.4.15)
Other considerations	Recommendation 1.4.12 was based on evidence statements AC6 and SP8. Evidence statement AC6 was about the lack of local specialist and crisis community services leading to out of area placements. The evidence suggested that lack of specialist and crisis community services resulted in out of area placements. The evidence in evidence statement SP8 suggested that when people were referred to a community forensic team there was a reduction in people living in out of area secure units and an increase of people living in the community under their care. Recommendation 1.4.13 was based on evidence statements SP8 and SP9. The evidence was about the effectiveness of Community forensic services and people's views and experiences of the services. The evidence related to SP8 found that specialist community forensic services were more likely to provide access to appropriate treatment services compared to general community

	services and secure services for people with a learning disability and forensic needs. The evidence related to SP9 suggested that people eligible for, a forensic community rehabilitation order or a community treatment order were able to live in the community and in the least restrictive setting. The committee discussed how support should be provided for this group and thought that the recommendation is particularly important for people in contact with the criminal justice system (a group highlighted through the Equality Impact Assessment). Recommendation 1.4.14 was based on evidence statement SP9 which was about people's views and experiences of community forensic services. The evidence suggested that some people felt isolated and they had very limited social networks in the community which meant that the contact they had with support staff was often their main relationship. Recommendations 1.4.13 and 1.4.14 was thought to be particularly important for people in contact with the criminal justice system (a group highlighted through the Equality Impact Assessment). Recommendation 1.4.15 was based on evidence statements SP9 and Int3. This is the same evidence, evidence statement SP9 about people's views and experiences of community forensic services and evidence statement Int3 about working with communities. The evidence related to SP9 suggested that people eligible for, a forensic community rehabilitation order or a community treatment order were able to live in the community and in the least restrictive setting. The evidence related to Int3 suggested that understanding and responding to any concerns in local neighbourhoods helps build relationships with neighbours, local councillors, and police and anti-social behaviour teams. This recommendation was thought to be particularly important for people in contact with the criminal justice system (a group highlighted through the Equality Impact Assessment). Recommendation 1.4.16 was based on evidence statements SP8 and Int4. This is the same evidence statement SP8 about the effectiveness of Community forensic services and evidence statement Int4 about linking health and social care. The evidence related to SP8 suggested that that specialist community forensic services were more likely to provide access to appropriate treatment services and professional input compared to general community services and secure services for people with a learning disability and forensic needs. The evidence related to evidence statement Int4 found that making links between different sectors helps services work together in a 'joined up' way. The Guideline Committee developed the recommendation from this evidence further by suggesting that establishing close links between services means that people can be referred quickly between these services to get the right support. Recommendation 1.4.16 was thought to be particularly important for people in contact with the criminal justice system (a group highlighted through the Equality Impact Assessment).

Topic/section heading	**Housing and day to day support**
Recommendations	Giving people a choice of housing Recommendations for local authorities, clinical commissioning groups and service providers 1.5.1 Commissioners should work with local housing and social care providers to identify the specific housing needs of adults with a learning disability and behaviour that challenges. They should ensure areas have a range of housing and care options available that meet these needs and cater for different preferences and person-centred support needs (see also section 1.2). 1.5.2 Enable adults to live close to their family, friends and community unless they choose not to or there is a compelling reason not to. 1.5.3 Where possible ensure that, wherever people live, they have security of tenure in line with the Real Tenancy Test. 1.5.4 When helping adults with a learning disability and behaviour that challenges choose where to live: • provide information on the range of possible options • take into account their preferences and any specific support needs or risks, including the impact of environmental factors on the person (see the recommendation on environmental factors in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions) • give them advice on adapting their current home if needed. 1.5.5 Offer people the option to live alone with appropriate support if they prefer this and it is suitable for them. 1.5.6 If adults prefer not to live alone with support, or it is not suitable for them, offer them the option of living with a small number of other people in shared housing that has a small-scale domestic feel. Involve people in choosing how many people, and who, they live with.
Research recommendations	What is the acceptability and feasibility of different house size/ residency for people of different support needs? What is the effectiveness and cost effectiveness of different household's sizes on incidence and severity of behaviour that challenges and quality of life for people with different support needs? What is the effectiveness and cost effectiveness of models of shared, supported living, such as Shared Lives? What are the views and experiences of people sharing their home and people who live with them under programmes such as Shared Lives?
Review questions	1.1. What is the effectiveness of different types of community based services (including residential) for children, young people and adults with learning disabilities and behaviour that challenges?

	1.3. What is the cost effectiveness of different types of services for children, young people and adults with learning disabilities and behaviour that challenges? 1.4. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different types of community and in patient services? 3.1. What models of service delivery are effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.2. What models of service delivery are cost effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.3. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different models of services delivery?
Quality of evidence	The evidence for these recommendations came from the review questions on types of services and models of service delivery. There was some research evidence on the effectiveness and cost effectiveness of different types of housing as a type of service for people with learning disabilities and behaviour that challenges. The strength of the evidence was inconclusive overall due to differences in populations, definitions and outcomes measured and different housing models in the individual studies. Study quality is mixed given the different types of included study designs for this review question and recommendations are based on a combination of research and Guideline Committee's experiential and practice based knowledge and expert witness testimony. The Guideline Committee felt there was a lack of high quality research in this area, and made research recommendations. We did not identify other studies of high quality that compared the effectiveness or cost effectiveness of one model of service delivery over another. In the absence of direct evidence, the review team included studies that might provide some insights in to how the whole system currently works or does not work. The studies included views and experiences about the barriers and facilitators identified by people who use services and professionals about models of care that include housing, and process evaluations about implementation of different models of housing and support. The review did not find full economic evaluation evidence for this review question (see 'economic considerations' below). Weaker study designs that included costs were included for consideration to offer insights as the potential costs and benefits but were not conclusive. These recommendations therefore rely on a combination of the research evidence, expert witness testimony and Guideline Committee expertise. Recommendation 1.5.1 was about commissioning accommodation is based on 8 evidence statements: EcH1, EcH2,

	EcH3, EcH12, EcH13, EcH17, EcH19, EcH23 and expert witness testimony from review question 2.1 in evidence statement DS06. Recommendation 1.5.2 was about deciding which services to put in place is based on 1 evidence statement SM18, derived from two UK moderate quality studies from review question 3.1. Recommendation 1.5.3 was about having the same rights of tenure as anyone else and was derived from expert witness testimony DS06 from review question 2.1 Recommendations 1.5.4 and 1.5.5 were about giving people choice is based on 8 evidence statements: EcH1, EcH2, EcH3, EcH12, EcH13, EcH17, EcH19, EcH23 and expert witness from review question 2.1 and expert witness from review question 2.1 in evidence statements DS06 and DS07 Recommendation 1.5.6 was about the size of shared housing is based on 3 evidence statements: EcH16, EcH17, EcH18.
Economic considerations	Limited evidence was identified relating to cost-effectiveness of housing models for people with learning disability and behaviour that challenges. Since there was limited research focusing specifically on individuals with learning disabilities and behaviour that challenges, additional searches were carried out that included studies that focused on individuals with learning disabilities, whether or not the sample included those with behaviour that challenges. However, the identified research literature lacked robust economic evaluations and a lack of ‘gold standard’ study designs more generally. None of the included studies were randomised control trials. This means the available evidence can provide an indication of impact, but we cannot be conclusive due to limitations of the study designs. These recommendations therefore rely on a combination of the research evidence, expert witness testimony and Guideline Committee expertise. Recommendations 1.5.1, 1.5.4 and 1.5.5 were based on 8 evidence statements. The evidence in recommendations EcH1, EcH2, EcH3, EcH12, EcH13, EcH17, EcH19 and EcH23 related to outcomes and costs of different types of housing. There was not any conclusive evidence to support one type of housing over another. The evidence suggested that for people with behaviour that challenges outcomes are better for people living in dispersed settings and supported living schemes. The evidence also found that people do worse in congregate or cluster housing settings. In terms of cost-effectiveness it was not possible to draw any firm conclusions. The view of the Committee was that recommendation 1.5.1 may require some investment. When there is effective communication and joint working between commissioners and local housing providers, this has the potential to better identify the range of housing available to suit the needs of the individuals they look after. When individuals receive housing and care that matches their needs and preferences, this is likely to be an efficient use of resources and is likely to lead to better outcomes. This is opposed to a scenario where commissioners provide housing based on incomplete information, which may mean an inefficient provision of resources.

	There was no cost-effectiveness evidence identified in relation to recommendation 1.5.2. The Guideline Committee took in to account likely resource impact associated with this recommendation, which is linked to the recommendation above about ensuring a range of provision is available locally. There was no cost-effectiveness evidence identified in relation to recommendation 1.5.3. The view of the Guideline Committee was that this was recognised good practice already. Recommendation 1.5.6 is supported by evidence statements EcH16, EcH17, and EcH18 which were based on reviews rated as having low to moderate quality. EcH17 finds that within community housing models, there were no economies of scale up to a residence size of 6, and beyond that, there were no additional economies of scale. The recommendation for small size group homes is supported by EcH16, which found consistent evidence from 3 reviews of low to moderate quality that small ordinary housing that is home-like, with standard architectural design, and physically integrated into the community have better outcomes for individuals than compared to individuals living in larger settings. Better outcomes included having low staff turnover, individuals having greater choice and opportunity for self-determination, and a positive effect on individuals' level of adaptive behaviour. The Guideline Committee also considered this evidence in the light of expert witness testimony, which suggested that living alone with support often supported people's wellbeing, and was associated with lower rates of placement breakdown.
Evidence statements – numbered evidence statements from which the recommendations were developed	DS06 (recommendation 1.5.1, 1.5.3 and 1.5.5) DS07 (recommendation 1.5.4) EcH1 (recommendations 1.5.1, 1.5.4, 1.5.5) EcH2 (recommendations 1.5.1, 1.5.4, 1.5.5) EcH3 (recommendations 1.5.1, 1.5.4, 1.5.5) EcH12 (recommendations 1.5.1, 1.5.4, 1.5.5) EcH13 (recommendations 1.5.1, 1.5.4, 1.5.5) EcH16 (recommendations 1.5.4, 1.5.6) EcH17 (recommendations 1.5.1, 1.5.4, 1.5.5, 1.5.6) EcH18 (recommendations 1.5.4, 1.5.5, 1.5.6) EcH19 (recommendations 1.5.1, 1.5.4, 1.5.5, 1.5.6) EcH23 (recommendations 1.5.1, 1.5.4, 1.5.4, 1.5.5) SM18, GC consensus (recommendation 1.5.2)
Other considerations	Recommendation 1.5.1 was about commissioning accommodation is based on 8 evidence statements. The evidence in recommendations EcH1, EcH2, EcH3, EcH12, EcH13, EcH17, EcH19 and EcH23 related to outcomes and costs of different types of housing. There was not any conclusive evidence to support one type of housing over another. The evidence suggested that for people with behaviour that challenges outcomes are better for people living in dispersed settings and supported living schemes. The evidence also found that people do worse in congregate or cluster housing settings. In terms of cost-effectiveness it was not possible to draw any firm

	conclusions. The expert witness testimony, DS06 and DS07, from the Devon case study said that in their experience it was very important for services to work together, including housing. The Guideline Committee developed the recommendation from this evidence to take into account that there is no single housing model to recommend, people have different preferences and support needs which may impact on the type of housing that is suitable for them. To address the lack of high quality research in this area, the committee has made 2 research recommendations about the acceptability, feasibility, effectiveness and cost effectiveness of different house size/residency for people with different support needs and the feasibility and effectiveness of models of shared, supported living, such as Shared Lives for people with learning disabilities and behaviour that challenges. Recommendation 1.5.2 was about supporting people to live near their families and communities is based on 1 evidence statement SM18 and Guideline Committee consensus. There was a small amount of evidence based on people's views and experiences that found families want local, small and specialist care close to their homes. Recommendation 1.5.3 was about security of tenure is based on committee consensus and expert witness from the Devon case study. The expert witness testimony, DS06 and DS07, from Devon strongly suggested that accommodation and support should not be interdependent. That way, if there is a breakdown with the service provider the person does not lose their home. Guideline committee members also understood this to be best practice. Recommendations 1.5.4 and 1.5.5 was about giving people choice is based on the same 8 evidence statements as 1.5.1 and the same rationale of the evidence applies here related to taking into account people's preferences. Reference to environmental factors and home adaptations were added to the recommendation based on GC consensus following stakeholder feedback. Recommendation 1.5.5 was based on expert testimony from the Devon case study that suggested that group living is rarely effective for people with behaviour that challenges. Given that the committee thought that people should be offered the option to live alone and there was no evidence to suggest that outcomes are worse for this group, the committee discussed what adaptations might be needed to support people living in their own home. Recommendation 1.5.6 about the size of shared housing is based on 1 evidence statement EcH17, and supported by evidence statements EcH16 and EcH18. The evidence found that there are economies of scale up to a residence size of 6, and that although smaller settings were more costly, the effect on costs was small. The research evidence was from one study and there was compelling evidence from the Devon case study that group living rarely works in terms of person-centred care given the range of needs that people may have. living. The research evidence EcH1 also found that grouping people based on the characteristics of

	their needs expressed by displaying behaviour that challenges or "congregateness" led to poorer outcomes for people

Topic/section heading	**Giving people a choice of housing accommodation**
Recommendations	1.5.7 Offer adults housing outside their local community only: • if it is what the person wants • if it is indicated after a full assessment and planning process, which takes into account the person's preferences, needs and risks • for a specified time that has been agreed with the person, or agreed in their best interests if they lack capacity to decide this – for example if they are in crisis and there is no local placement available. 1.5.8 If someone is moving outside their local area, local authorities, clinical commissioning groups and commissioners should: • establish the commissioner who is responsible for paying for the person's care and support • ensure they will still have the support they need • make a plan that enables them to return to their local area if they want to, or if it is in their best interests if they lack capacity to decide this.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	1.1. What is the effectiveness of different types of community based services (including residential) for children, young people and adults with learning disabilities and behaviour that challenges? 1.3. What is the cost effectiveness of different types of services for children, young people and adults with learning disabilities and behaviour that challenges? 2.1 What is the appropriate community-based service capacity for people with learning disabilities and behaviour that challenges, and their families and carers? 1.4. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different types of community and in patient services? 3.1. What models of service delivery are effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.2. What models of service delivery are cost effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.3. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that

	challenges, their families and carers of different models of services delivery? 5.2 What helps to make services more joined up with the person and their family?
Quality of evidence	The evidence for these recommendations came from the review questions on appropriate service capacity, types of services and models of service delivery and integration. There was little direct research evidence about the effectiveness of types of services compared to other services or no services, the appropriate service capacity for community services or models of services delivery. In the absence of research evidence that directly answered these questions the review team presented evidence from studies that examined characteristics of service use, people's views and experiences to barriers and facilitators to access and take up of services, and studies that reported on potentially negative outcomes such as out of area placements or delayed discharges associated with lack of provision of community services. These recommendations are a combination of the research evidence and Guideline Committee expertise. Recommendation 1.5.7 was about providing accommodation outside the local community is based on 10 evidence statements: SP3 from review question 2.1 and EcAC1, EcAC2, EcAC3, EcH5, EcH8, EcH6, EcH9, EcH10, and EcH11 from review question 1.1 about housing. Evidence statement SP3 is derived from 1 low quality UK non-randomised, matched-group study. Evidence statement EcAC1 is derived from 1 low quality study. Evidence statement EcAC2 is derived from 2 mixed quality studies, 1 low and 1 moderate quality. Evidence statement EcAC3 is derived from 4 mixed quality studies, 2 low and 2 moderate quality. Evidence statement EcH5 is derived from 1 low quality study. Evidence statement EcH8 is derived from 3 mixed quality studies, 2 moderate and 1 low quality. Evidence statement EcH6 is derived from 2 low quality studies. Evidence statement EcH9 is derived from 2 moderate quality studies. Evidence statement EcH10 is derived from 1 low quality study. Evidence statement EcH11 is derived from 1 high quality study. Recommendation 1.5.8 was about people placed outside their local area, is based on 3 evidence statements: SP3 from review question 1.1, Int9 from review question 5.2, AC8 from review question 2.1. Evidence statement SP3 is derived from 1 low quality UK non-randomised, matched-group study. Evidence statement Int9 is derived from 3 mixed quality studies, 2 moderate quality and 1 low quality. Evidence statement AC8 is derived from 5 mixed quality studies, 4 low quality and 1 moderate quality.
Economic considerations	These recommendations were supported by economic evidence statements: EcAC1, EcAC2, EcAC3, EcH5, EcH6, EcH8, EcH9, EcH10, and EcH11. Overall, the cost-effectiveness evidence relating to housing is limited due to the lack of robust study designs. However, overall the evidence suggested that out of area placements were either the same of more expensive than in-area placements, and did not lead to better outcomes. Some quality of life outcomes were slightly worse.

	Evidence statement EcH11 is based on a good quality study which finds that individuals in out-of-area placements, compared to those living in in-area placements had greater rates of multiple types of abuse, physical abuse, psychological abuse, neglect, institutional, and discriminatory abuse. Evidence statement EcH10 is based on a low quality study finding that individuals in out-of-area placements did worse in some areas of health outcomes and some areas of quality of life outcomes. Evidence statement EcH9 is based on 2 studies of moderate quality finding mixed evidence regarding standards of care among individuals with the highest cost care packages when comparing those living in-area vs. out-of-area. Evidence statement EcH8 is based on mixed evidence from 3 low to moderate quality studies finding among individuals with the highest cost care packages, that the costs of out-of-area placements were either the same as or slightly higher than individuals living in in-area placements. Evidence statement EcH6 is based on consistent evidence from two low quality studies which find that people in out-of-area placements did not necessarily receive superior services even though the placements assumed they would receive higher levels of care. Evidence statement EcH5 is based on 1 low quality review finding that among individuals with intellectual disabilities, out-of-area placements cost more than those in in-area placements, but this may be due to individuals having greater levels of needs. Evidence statement EcAC1 is based on a low quality study finding that individuals with intellectual disabilities living in out-of-area placements were more likely to live in institutional settings. Evidence statement EcAC2 is based on the same 1 low quality study finding that out-of-area placements had greater access to some types of services compared to those living in in-area placements. Evidence statement EcAC3 finds that for adolescents and adults with learning disabilities and complex mental health needs, out-of-area placements cost more than in-area placements but that for those with severe learning disabilities and physical and behavioural problems out-of-area placements and in-area placements had similar costs. The Guideline Committee considered this evidence in the light of other evidence, and their own experience and knowledge, that people prefer to live close to their families and communities. This led them to recommend that people should be offered accommodation in their local area wherever possible (recommendation 1.5.7).
Evidence statements – numbered evidence statements from which the recommendations were developed	AC8 (recommendation 1.5.8) EcAC1 (recommendation 1.5.7) EcAC2 (recommendation 1.5.7) EcAC3 (recommendation 1.5.7) EcH5 (recommendation 1.5.7) EcH8 (recommendation 1.5.7) EcH6 (recommendation 1.5.7) EcH9 (recommendation 1.5.7) EcH10 (recommendation 1.5.7) EcH11 (recommendation 1.5.7)

	Int9 (recommendation 1.5.8) SP3 (recommendation 1.5.7, 1.5.8)
Other considerations	Recommendation 1.5.7 was about providing accommodation outside the local community is based on 1 evidence statement (SP3) and committee consensus. It is also supported by a further 9 economic evidence statements: EcAC1, EcAC2, EcAC3, EcH5, EcH8, EcH6, EcH9, EcH10, EcH11. The research related to evidence statement SP3 found that for people placed in area, there were few differences in quality of life except they had more social activities and social contact. The Guideline Committee developed this evidence further based on their practice and experience to recommend that people should only offer people accommodation outside their local area if there is a good reason to do so, for example, if the person has offended and the victims live in their local area. The recommendation is supported by a further 9 evidence statements about the effectiveness and cost effectiveness of placing people out of area. The cost-effectiveness evidence relating to housing was limited due to the lack of robust study designs. However, overall the evidence suggested that out of area placements were either the same of more expensive than in-area placements, and did not lead to better outcomes. Some quality of life outcomes were slightly worse. The Guideline Committee thought it was important that people should not be forced to move out of area because of a lack of suitable support services. Recommendation 1.5.8 was about people placed outside their local area, is based on 3 evidence statements: SP3, Int9 and AC8. The research related to evidence statement SP3 found that for people placed in area, there were few difference in quality of life except they had more social activities and social contact. The Guideline Committee developed this evidence further based on their practice and experience to recommend that reviews and plans be put in place to enable people to return to their local area. The recommendation is also supported by a further 2 evidence statements about the importance of regular reviews. The research related to evidence statement Int9 was about the importance of having regular reviews. The research related to evidence statement AC8 suggested that as part of quality assurance, children placed out of area should have their progress regularly reviewed. The Committee also discussed the importance of identifying the responsible commissioner as a way of ensuring that a person's needs are met.

Topic/section heading	**Services for children and young people**
Recommendations	Recommendations for local authorities, clinical commissioning groups and the lead commissioner 1.6.1 Local authorities should ensure that parents and carers of children and young people with a learning disability and behaviour that challenges have support to care for their child (see section 1.3)

	1.6.2 Local authorities must promote the upbringing of children and young people with a learning disability and behaviour that challenges by their families, in line with section 17 of the Children Act 1989. This should include providing a range of services including education, and general and specialist learning disability support services in the community, as an alternative to residential placements away from home and to reduce the potential need for such placements. 1.6.3 The lead commissioner should ensure that specialist behavioural support in the community for children and young people includes support from education and child and adolescent mental health service (CAMHS) practitioners who have skills and experience in working with children and young people with a learning disability and behaviour that challenges. Recommendations for local authorities, service providers and practitioners 1.6.4 Health, mental health and behaviour support practitioners should work with other services, for example education and social care, to: • deliver the outcomes agreed in a child or young person's education, health and care plan • provide support and interventions in line with NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions • maximise life opportunities for children and young people, including by ensuring they have access to meaningful education • support smooth transitions between services in line with organising effective care in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions • support children and young people to develop skills for independence • take a positive approach to managing risk. This applies to children and young people in residential placements, as well as those living at home. 1.6.5 If a child or young person's behaviour that challenges is deteriorating or causing concern, the local authority should carry out a multi-agency review of their education, health and care plan (or other relevant plan) and involve the child or young person and their parents or carers. Review whether the plan needs to be updated and additional support provided if the child or young person's needs have changed.
Research recommendations	What types of interventions are effective in helping children and young people with a learning disability and behaviour that challenges to stay in school? What are the effective components of an integrated regional challenging behaviour service across health and social care (including pooling budgets and other resources)? What are the barriers and facilitators to pooling budgets and other resources across regions?

	What interventions are effective in supporting families, carers and staff to be resilient and able to provide care and support to people with a learning disability and behaviour that challenges?
Review questions	2.1 What is the appropriate community-based service capacity for people with learning disabilities and behaviour that challenges, and their families and carers? 3.1. What models of service delivery are effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.2. What models of service delivery are cost effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.3. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different models of services delivery? 4. What models of service delivery facilitate timely access to effective and cost-effective services for children, young people and adults with learning disabilities and behaviour that challenges?
Quality of evidence	Overall, we found limited direct evidence relating to effective models of care for any group, including for children and young people. A number of research recommendations were made in this area. Indirect evidence from process evaluation and views and experiences studies on the limitations of current service provision were identified. In some cases these were focused on adults, but the findings were extrapolated to children's services. The committee's recommendations focused on addressing the limitations in current service provision identified in these studies. There was also evidence on views and experiences of the families of children and young people, including one high quality UK survey of parents and families, which were able to inform the recommendations. Recommendations 1.6.1 and 1.6.3 were based on 1 evidence statement AC9 derived from 4 low quality UK studies from review question 2.1. Recommendation 1.6.2 was based on one evidence statement (SM10) on the barriers and facilitators to maintaining family life and was derived from two studies, one study from Canada of low quality and 1 UK study of high quality from review question 3.3. Recommendation 1.6.4 and 1.6.5 were based on 1 evidence statement SM12 based on 3 UK studies, 2 low quality and 1 high quality study from review question 3.3.
Economic considerations	There was no cost-effectiveness research relating to these recommendations. The Guideline Committee considered the potential resources required. For recommendations 1.6.1 and 1.6.3, the committee thought that this would represent a more effective use of local resources by making use of specialist skills already present. Recommendation 1.6.2 reflects statutory requirements, meaning that local authorities should already be working in this way. Recommendation 1.6.4 has potential resource implications in

	terms of provision of interventions in line with the clinical guideline. Recommendation 1.6.5 has some potential resource implications, but these may be offset by prevention of breakdown of existing arrangements for a child or young person.
Evidence statements – numbered evidence statements from which the recommendations were developed	AC9 (recommendation 1.6.1 and 1.6.3) SM10 (recommendation 1.6.2) SM12 (recommendation 1.6.4, 1.6.5)
Other considerations	Recommendations 1.6.1 and 1.6.3 was based on evidence statement AC9 which found that local services often did not people's needs, but that shared commissioning for services could be more effective in meeting needs for people locally. Much of the evidence related to services for adults. The committee extrapolated this evidence to services for children and young people, and ensuring that good use was made of expertise within local CAMHS services. Recommendation 1.6.2 was based on evidence statement SM10 which related to the barriers and facilitators to maintaining family life. Barriers to maintaining family life included the lack of local support leading to placement in residential school, which made it even more difficult to maintain normal family life. The Guideline Committee noted that local authorities have a statutory duty to support the upbringing of children within their families wherever possible, and that addressing the barriers to this was part of this role. Recommendation 1.6.4 and 1.6.5 were based on evidence statement SM12 which related to respite and short breaks for children and Guideline Committee consensus. The Guideline Committee discussed how children can be excluded from school and find themselves excluded from other services as well, because of the label ‘behaviour that challenges’. They talked about how respite care needs are greater when behaviour is more challenging (such as when children are excluded) but that this is a time when it can be hardest to get it. The committee also noted that, if many services are provided via school, then exclusion from school can mean lack of access to other necessary services. It was the view of the committee that education service providers should take a preventive approach to excluding children from school by reviewing and revising the ECHPs as soon as there is concern. Following stakeholder feedback we added clarification that this applies to children and young people living in residential placements, as well as those living at home. We further revised this recommendation following stakeholder feedback that health, mental health and behaviour support practitioners should work with other services, for example education and social care to support children and young people in developing skills for independence. For recommendation 1.6.5 the Guideline Committee also discussed the importance of education services

	being more knowledgeable about behaviour that challenges and their role in delivering the Education Health and Care Plan. The Guideline Committee thought that there was not enough high quality research evidence about approaches or interventions that are effective for preventing exclusion and supporting children and young people to stay in school and effective tools to deliver good outcomes for children and young people with learning disabilities and behaviour that challenges. The committee has made 2 research recommendations in this area.

Topic/section heading	**Exploring alternatives to residential placements**
Recommendations	Recommendations for the lead commissioner, service providers and practitioners 1.6.6 Support parents and carers to understand the full range of options for education, care and support for their child. 1.6.7 When considering a residential placement, arrange a multi-agency review to explore all options and to review the child or young person's education, health and care plan. Include in this discussion: • the child or young person and their parents or carers • the lead commissioner on behalf of the local authority and clinical commissioning group • at least 1 practitioner with clinical expertise in learning disability and the specific behaviour that is challenging. • an independent expert by experience • special educational needs staff, or staff from their school or college. 1.6.8 Only offer children and young people a residential placement: • if assessment and care planning show that their needs (including their educational needs) cannot be met while they are living at home, and all alternatives to residential care have been considered and exhausted, or • following a request by the child or young person's family, which has been considered under the Children and Families Act 2014.
Research recommendations	What types of interventions are effective in helping children and young people with a learning disability and behaviour that challenges to stay in school? What are the effective components of an integrated regional challenging behaviour service across health and social care (including pooling budgets and other resources)? What are the barriers and facilitators to pooling budgets and other resources across regions? What interventions are effective in supporting families, carers and staff to be resilient and able to provide care and support to people with a learning disability and behaviour that challenges?

Review questions	3.1. What models of service delivery are effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.2. What models of service delivery are cost effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.3. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different models of services delivery?
Quality of evidence	Overall, we found limited direct evidence relating to effective models of care for any group, including for children and young people. A number of research recommendations were made in this area. We found evidence on views and experiences of the families of children and young people, including one high quality UK survey of parents and families, which were able to inform the recommendations. The advice of the Guideline Committee was that a similar approach should be taken to residential care as to inpatient settings; these recommendations have therefore taken account of this evidence, including expert witness testimony on inpatient care. Recommendation 1.6.6 was based on one evidence statement SM10 that related to barriers and facilitators to family life. This was derived from 2 studies of families' views and experiences: 1 low quality study from Canada and 1 high quality UK study.
Economic considerations	There was no cost-effectiveness research relating to these recommendations. However, the Guideline Committee were mindful of the potential resource impact of these recommendations. For both recommendations 1.6.7 and 1.6.8 it was the Guideline Committee view based on practice and experience that increasing investment into community services and supports for families will reduce costs as it will reduce the need and use of residential placements. Increasing capacity of community based services to support children and young people to remain at home is a key part of Transforming Care agenda and so local authorities should already be undertaking these changes as part of implementing this agenda.
Evidence statements – numbered evidence statements from which the recommendations were developed	SM10 (recommendation 1.6.8)
Other considerations	Recommendation 1.6.6 was a consensus recommendation based on Guideline Committee consensus following stakeholder feedback that we had not considered the conditional duties of Local Authorities to meet parental choice of residential school, if that is what they chose. The Guideline committee referred to the evidence that families said that the choice of a residential school was made on partial information or based on the lack of alternatives locally, a new recommendation was added to address

	the balance between Local authorities duties regarding parental choice and making sure that parents had all the information needed to make an informed choice. Recommendation 1.6.7 was a consensus recommendation based on experience and practice that follows from the evidence in 1.6.6 that the Education Health and Care Plan should be the mechanism for exploring all other alternative to moving children away from their home. Following stakeholder feedback, this was clarified that the review to explore all other options than moving away from home should include people from the child's educational setting, such as the special educational needs team or other staff from the school or college. Recommendation 1.6.8 was based on evidence statement SM10 which related to the barriers and facilitators to family life. The evidence pointed to lack of supports leading to residential care placements. The Guideline Committee noted that the same rigour in finding alternatives to inpatient admission for adults should be applied to children who are being considered for placement away from home. The recommendation was also revised to include reference to Local Authorities conditional duties to provide educational placements that the families have chosen, following from recommendation 1.6.6 that families should be supported to access relevant information including all alternatives to residential placements.

Topic/section heading	**Living in residential placements and planning and review to support leaving residential placements**
Recommendations	Recommendations for local authorities, clinical commissioning groups and service providers 1.6.9 Commission residential placements for children and young people as close to home as possible. Take into account in local authority contracts that some families may need financial support to help them see their child and for their child to visit them. 1.6.10 Support children and young people to maintain links with their family, friends and community (for example, members of their religious community) while they are in a residential placement. 1.6.11 Local authorities and service providers must promote maximum contact between children and young people living in residential placements and their family members and carers (in line with schedule 2 of the Children Act 1989). If a placement lasts longer than 3 months the Visiting Regulations 2011 must be followed, for both local and out-of-area placements. Help families stay in touch between visits, for example using Skype. Planning and review to support children and young people leaving a residential placement Recommendations for local authorities, clinical commissioning groups and practitioners 1.6.12 As soon as a child or young person moves into a residential placement local authorities and clinical commissioning groups should ensure that:

	- a plan is developed for how they will progress towards returning to their family home, if appropriate, and towards greater independence - they continue to be supported to meet the outcomes identified in their education, health and care plan. 1.6.13 Review the plan in recommendation 1.6.12 at least every 6 months to check that progress is being made. This could be done as part of a looked-after child review, an education, health and care plan review, or sooner if needed. 1.6.14 Plans should be reviewed by the practitioner responsible for overseeing the child or young person's education health and care plan and all other practitioners involved in their care and support, including a specialist in behaviour that challenges. 1.6.15 If progress towards the outcomes in the plan has not been made, explore and address the reasons for this. If the child, young person or their family disagrees with the decision made at the review meeting, explain how they can challenge the decision if they want to.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	2.1. What is the appropriate community-based (including residential care) service capacity for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 2.2. What is the appropriate inpatient bed capacity (local and out of area) for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.3. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different models of services delivery?
Quality of evidence	There was relatively little evidence relating to effective service models or appropriate capacity for children and young people's services. The recommendations therefore also drew on the professional experience of the Guideline Committee, including 2 consensus recommendations, and extrapolation from expert witness testimony on inpatient settings. We found some evidence relating to views and experiences of parents and families and some evidence from process evaluation and cross-sectional studies. The process evaluation and cross-sectional studies related to inpatient units but findings relating to discharge were extrapolated to residential settings. Recommendations 1.6.9, 1.6.10 and 1.6.11 were based on 1 evidence statement SM8 which was derived from 1 high quality and 1 low quality views and experience studies. Recommendation 1.6.15 was based on 1 evidence statement AC20 which was derived from 1 low quality evaluation, 1 low quality study and 1 moderate quality study relating to inpatient settings.

Economic considerations	There was no cost-effectiveness research relating to these recommendations. However, the Guideline Committee were mindful of the potential resource impact of these recommendations. For recommendations 1.6.9 and 1.6.10 the committee drew on their experience which suggested that investment in local residential settings would reduce the cost shifting onto families to maintain family life when visiting their loved one in residential care. Recommendation 1.6.11 is aligned with statutory duties and so should not have an additional resource impact. For recommendations 1.6.12 to 1.6.15 it was the view of the committee that regular review of people's care needs with a view to moving people to less restrictive settings will likely result in savings over the long term as people reduce service use only for as long it is needed and is of benefit.
Evidence statements – numbered evidence statements from which the recommendations were developed	AC20 (recommendation 1.6.15) SM8 (recommendation 1.6.9, 1.6.10, 1.6.11)
Other considerations	Recommendations 1.6.9, 1.6.10 and 1.6.11 were based on evidence statement SM8, which found the way services were organised and paid for could be a barrier to good care. Parents also said that in can be difficult to get help to stay in touch with their children in they are in a residential schools all year. The Guideline Committee developed this further based on their practice and experience that that residential care services should work with families and carers to maintain contact and relationships with children and young people. This recommendation also considered the economic impact on families from low socio-economic groups (a group highlighted through the Equality Impact Assessment). Recommendations 1.6.12, 1.6.13 and 1.6.14 were consensus recommendations that follow on from agreement that practice in relation to residential care services for children and young people should be aligned with recommendations on inpatient service provision. Namely, where a child or young person has been placed in residential care, plans should also be explored to move them back home again, or towards supporting greater independence as they get older. The existing Education Health and Care Plan could be used as the mechanism for ensuring this review takes place. Recommendation 1.6.15 was based on evidence statement AC20 which was about planning for discharge. This was supported by expert witness testimony in relation to inpatient admissions, which was extrapolated to residential settings. The Guideline Committee developed the recommendations from this evidence further by aligning the same recommendations about inpatient admission for adult to children who are being considered for moving from their

	home or who now live in residential care. The inpatient admission and discharge process includes the right to review and challenge and the Guideline Committee said this was important for children young people and families in relation to residential placements as well.

Topic/section heading	**Short break services**
Recommendations	Recommendations for local authorities, commissioners and service providers 1.7.1 Local authorities must, in line with the Breaks for Carers of Disabled Children Regulations 2011 and the Children and Families Act 2014: • provide a range of short breaks for children and young people with a learning disability and behaviour that challenges, and • publish as part of their Local Offer a statement of the range of services available and how eligibility will be assessed,. 1.7.2 Commissioners in health and social care should provide sufficient, reliable, flexible and varied short break options, including both breaks away and support at home, for adults with a learning disability and behaviour that challenges. 1.7.3 Ensure that short breaks are: • community-based and close to home • available based on need, and at short notice both in crisis and to prevent a crisis • tailored to the needs of the person and their family or carers, taking into account the person's interests and preferences • able to provide a positive experience for the person being supported • able to deliver what is agreed in the education, health and care plan or care and support plan; carer's assessment; or behaviour support plan • planned in advance wherever possible and involve people and their family members and carers visiting the service first to see if it is suitable and to get to know the staff providing it • provided by staff who understand and respect people's cultural norms and values and their choices about personal care, private life and lifestyle.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	1.1. What is the effectiveness of different types of community based services (including residential) for children, young people and adults with learning disabilities and behaviour that challenges?

	1.3. What is the cost effectiveness of different types of services for children, young people and adults with learning disabilities and behaviour that challenges? 3.1 What models of service delivery are effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.3. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different models of services delivery? 4. What models of service delivery facilitate timely access to effective and cost-effective services for children, young people and adults with learning disabilities and behaviour that challenges?
Quality of evidence	There was no evidence from study designs that could reliably detect the effectiveness or cost-effectiveness of respite care as a type of service. Additional economic modelling was undertaken to assess the potential cost-effectiveness of additional respite care (see 'economic considerations' below). There was also evidence from views and experiences studies which highlighted the importance of respite care in supporting families and carers. Studies also looked as the association between the lack of respite care and negative outcomes, such as placement breakdown, placement of children in residential care or out of area placement. For this reason Guideline Committee made a potentially resource-intensive recommendation for respite care. There were few high quality studies that compared different models of service delivery that include respite care. The Guideline Committee therefore considered evidence from views and experiences of people who used respite care and other studies that make associations with positive and negative outcomes with respite care. The Guideline Committee considered this evidence in light of their own experiences and expertise. Recommendations 1.7.1 and 1.7.2 were about commissioning respite care were based on 5 evidence statements: SM12 and SM36 from review question 3.3, SM37 from review question 3.1 , SP5 from review question 1.1 and AC1 from review question 4. Evidence statement SM12 was derived from 3 UK studies of mixed quality, 2 low quality and 1 high quality. Evidence statement SM36 was derived from 3 low quality studies. Evidence statement SM37 was derived from 2 studies of mixed quality, 1 low quality and 1 high quality. Evidence statement SP5 was derived from 3 UK studies of mixed quality, 2 moderate quality and 1 high quality. Evidence statement AC1 was derived from 2 studies of mixed quality, 1 moderate quality and 1 high quality. Recommendation 1.7.3 about factors to take into account when planning respite care is based on 3 evidence statements: SM12 and SM37 from review question 3.1 and AC3 from review question 4. Evidence statement SM12 was derived from 3 UK studies of mixed quality, 2 low quality and 1 high quality. Evidence statement SM37 was derived from 2 studies of mixed quality, 1 low quality and 1 high quality. Evidence statement AC3 was derived from 2 mixed quality studies, 1 moderate and 1 high.

Economic considerations	No cost-effectiveness studies relating to respite care were identified. Additional economics work was undertaken in the form of threshold and scenario analyses to identify when assumptions on costs and QALYs would have to be true in order for different intensities and costs of respite care to be cost-effective. The additional analysis indicated that different intensities of respite care can be cost-effective when compared to the possibility of a placement breakdown that requires a residential placement. The analysis showed that when the individual is living at home, the provision of additional respite care can be cost-effective if residential care can be avoided. Refer to Appendix C2 for the full economic analysis and details.
Evidence statements – numbered evidence statements from which the recommendations were developed	AC1 (recommendation 1.7.1, 1.7.2, 1.7.3) AC3 (recommendation 1.7.3) SM12 (recommendation 1.7.1, 1.7.2, 1.7.3) SM36 (recommendation 1.7.1, 1.7.2, 1.7.3) SM37 (recommendation 1.7.1, 1.7.2, 1.7.3) SP5 (recommendation 1.7.1, 1.7.2, 1.7.3)
Other considerations	Following stakeholder feedback the term "respite" was replaced with "short breaks" while this has particular meaning and legislative duties when this is meant for children and young people, the feedback strongly indicated that the term respite was no longer a term that was viewed positively. We clarified our broader meaning of the term "short breaks" to mean breaks of short duration, either at home or away from home for children, young people and adults in the terms used section and used the term in the recommendations. The research evidence in this area typically used the term 'respite' and we have retained the term when we describe the research evidence and the Guideline Committee considerations of the evidence. Recommendations 1.7.1 and 1.7.2 were based on evidence statements SM12, SM36, SM37, SP5 and AC1 and the outcome of the economic modelling (see above). Evidence statement SM12 was about people's views of respite care for children and AC1 was about access to respite care. This evidence suggested that access to respite can be poor due to low availability and low quality of services. The evidence here also pointed to what type of respite families wanted which has been incorporated into the recommendation and the notion that respite should be based on needs and outcomes to be achieved, rather than diagnosis. Evidence statements SM36 and SM37 were about supporting families to prevent alternative residential placements or out of area placements. The evidence in evidence statement SM36 found that if families received support in the home, such as respite or if short breaks were provided it could help prevent residential placements for young people at risk of moving to residential care from breaking down. Evidence statement SP5 was about respite services and impact on family functioning. The evidence suggested that the availability of respite care or other part time residential options can prevent

	the deterioration of the family’s ability to cope over time, and may prevent full time residential placements and hospital admissions. The evidence was supported by the Guideline Committee’s own professional and personal experiences about the importance of respite, and the role it can play in helping to prevent people moving to costly residential placements, including out-of-area placements. The view of the committee was that, it line with other discussions about services, both respite and short breaks should be tailored to meet the needs of individuals. The committee thought that respite should be a positive experience for the person supported, not just a holding exercise while the carers have a rest. Recommendation 1.7.3 was based on evidence statements AC1, AC3, SM12, SM36, SM37 and SP5. AC1 was about access to respite care. This evidence suggested that access to respite can be poor due to low availability and low quality of services. The evidence here also pointed to what type of respite families wanted which has been incorporated into the recommendation and the notion that respite should be based on needs and outcomes to be achieved, rather than diagnosis. Evidence statement AC3 was about the barriers black and minority ethic families face when accessing respite care. The evidence suggested that it helps if support workers understand and respect people’s cultural norms and values. Evidence statement SM12 was about people's views of respite care for children, the Guideline Committee discussed the importance of taking into account the interests and preferences of the person. Evidence statements SM36 and SM37 were about supporting families to prevent alternative residential placements. The evidence suggested that if families were better supported at home to be able to make sure the Positive Behavioural Support plan was implemented properly this could prevent them from having to seek an alternative residential placement. In addition, evidence statement SP5, about respite services and the impact on family functioning suggested that the availability of respite care or other part time residential options can prevent the deterioration of the family’s ability to cope over time, and may prevent full time residential placements and hospital admissions. The committee developed the recommendations from this evidence further, especially with the input from the experts by experience in the committee to recommend giving people a chance to get to know the people providing their respite before it begins. he experts by experience in the committee developed this recommendation further by suggesting that people and their family members and carers should be supported to visit respite services before using them to see if they are suitable. 1.7.3 also addressed the needs of people with different ethnicity, religion or beliefs (a group highlighted through the Equality Impact Assessment).

Topic/section heading	**Making the right use of inpatient services**
Recommendations	Exploring alternatives to inpatient admission Recommendations for commissioners, service providers and practitioners 1.8.1 Admit children, young people and adults with a learning disability and behaviour that challenges to inpatient units only if assessment and care planning show that their needs cannot be met safely in the community, and all possibilities for doing so have been considered and exhausted. 1.8.2 When thinking about inpatient admission, arrange a discussion to explore all other viable options. Include in this discussion: • the person and their family members and carers • at least 1 practitioner with clinical expertise in learning disability and the specific behaviour that is challenging • at least 1 independent expert by experience. For further guidance, see NHS England's information on community Care and treatment reviews or, for children and young people, community Care, education and treatment reviews. Providing information Recommendations for local authorities, clinical commissioning groups and service providers 1.8.3 When there is a possibility that someone will be admitted to hospital, including as an informal admission, local authorities and clinical commissioning groups should give them and their family and carers accessible, independent information and advice about their rights, access to independent advocacy and other possible options for treatment, and care and support. 1.8.4 Service providers must provide information about independent mental health advocacy as required by the Mental Health Act 1983.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	2.1. What is the appropriate community-based (including residential care) service capacity for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 2.2. What is the appropriate inpatient bed capacity (local and out of area) for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.3. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different models of service delivery? 4. What models of service delivery facilitate timely access to effective and cost-effective services for children, young people and adults with learning disabilities and behaviour that challenges?

Quality of evidence	There was limited, direct research evidence about the appropriate service capacity for inpatient or community services. In the absence of research evidence that directly answered these questions the review team presented evidence from studies that could report on the studies that examined characteristics of service use, people's views and experiences to barriers and facilitators to access and take up of services and studies that reported on potentially negative outcomes such as out of area placements or delayed discharges associated with lack of provision of community services. Due to the lack of robust research evidence and expert witness from inpatient services was invited. These recommendations are based on the limited amount of research evidence, expert witness testimony and the Guideline Committee's experiential and practice based knowledge. Recommendation 1.8.1 was supported by 6 evidence statements: AC6, AC1, AC11, AC19, AC23 and SM18. Evidence statement AC6 about the availability of community provision from review question 2, was based on 4 studies, 2 moderate and 2 low quality. Evidence statement AC1 about access to respite from review question 4 was based on 2 studies, one high and one moderate quality. Evidence statement AC11 on integration of specialist and general services in the community from review question 4 was based on 4 studies, 1 moderate quality and 3 low quality. Evidence statement AC19 on delayed discharge from review question 2.2 was provided by three studies: 2 poor quality and 1 moderate quality. Evidence statement AC23 on types of inpatient services from review question 2.2 was provided by two low quality studies. Evidence statement SM18 about people's views and experiences of how services should be configured from review question 3.3 was based on 2 moderate quality qualitative studies. This was further supported by evidence in expert testimony IP01 from a clinical psychiatrist and DS08 from a case study of services in Devon. The remaining recommendations were based on expert witness testimony or Guideline Committee consensus. Recommendation 1.8.2 was further supported by evidence in expert witness testimony IP01 from a clinical psychiatrist and recommendation 1.8.3 was further supported by evidence in expert witness testimony DS08 from a case study of services in Devon.
Economic considerations	No relevant cost effectiveness evidence was identified for these recommendations. For recommendation 1.8.1 the committee acknowledged that meeting this recommendation would require some areas to increase capacity in community services, which had a potential resource implication. However, the view of the committee was that improving community provision to reduce use of inpatient services is a key part of Transforming Care and Building the Right Support, and so local authorities should already be undertaking these changes as part of implementing this agenda. In developing recommendations 1.8.2 to 1.8.3 the Guideline Committee were mindful of resource implications, aiming to ground recommendations in existing procedures and provision rather than introducing new requirements.

Evidence statements – numbered evidence statements from which the recommendations were developed	These recommendations are supported by: AC1 (recommendation 1.8.1) AC6 (recommendation 1.8.1) AC11 (recommendation 1.8.1) AC19 (recommendation 1.8.1) AC23 (recommendation 1.8.1) DS08 (recommendation 1.8.1, 1.8.3) IP01 (recommendation 1.8.1, 1.8.2) SM18 (recommendation 1.8.1)
Other considerations	Recommendation 1.8.1 was based on evidence statements SM18 from review question 3.1, evidence statement AC1 from review question 4, evidence statement AC6 from review question 2.1, and evidence statement AC23 from review question 2.2. This included evidence in evidence statement SM18 relating to the need for inpatient services to be 'joined up' with services in the community, evidence in AC1 and AC6 about the relationship between availability of community provision, including respite care, and admissions, and evidence AC23 about the types of inpatient services that should be available. It was further supported by evidence statement AC19 on delayed discharge, and the fact that many admissions to hospital are 'social admissions' which are not related to clinical need. The committee considered expert testimony IP01 from a clinician working in inpatient services and their own experience that often inpatient admissions were due to local services not identifying appropriate provision in the community. They also considered expert witness testimony DS08 from a case study of services in Devon which suggested that people with learning disabilities are better supported and have more positive outcomes if they are supported to live in the community, rather than being in hospital. The wording of the recommendation acknowledges, however, that there are still some instances in which admission is appropriate, including the safety of that person or others in their community. Following stakeholder feedback, the recommendation was revised to clarify that the existing Care and Treatment review framework could be used for adults to support discharge and for children and young people the Care, Education and Treatment Review or Education, Health and Care Planning process. Recommendation 1.8.2 was based on expert witness testimony IP01 from a clinician working in inpatient services, who stated that an example of good practice is to hold a multi-agency review meeting prior to admission, to ensure that all other options have been considered. The committee thought that the Care and Treatment review process (or Care, Education and Treatment Review process for children) were existing mechanisms by which these discussions could be held, and therefore did not represent an additional cost. These were given as examples to reflect the fact that there may be other mechanisms for holding these discussions. Recommendation 1.8.3 was based on expert witness testimony DS08 from a case study of services in Devon which suggested that, on some occasions, people consented to be admitted to

	hospital because they thought it was their only option. The committee therefore developed a recommendation about the provision of good quality, accessible information and advice for people prior to admission. Recommendation 1.8.4 was a consensus recommendation, highlighting that services have a duty to provide information about mental health advocacy according to the Mental Health Act 1983.

Topic/section heading	**Selecting a placement when required**
Recommendations	Recommendation for local authorities and clinical commissioning groups 1.8.5 Provide an inpatient placement that is as close as possible to where the person usually lives. Recommendations for inpatient services and community learning disability teams, including the named worker 1.8.6 The named worker should support the person to maintain links with their family, friends and community (for example, members of their religious community) while they are in hospital, and give their family and friends information about their progress. 1.8.7 If people are admitted as inpatients outside their local area, social workers in the community learning disability team and the named worker should stay in contact with the person, and help them stay in contact with other key practitioners in their own area. 1.8.8 When someone is admitted as an inpatient, offer them interventions in line with recommended psychological and environmental interventions in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions. Ensure that these interventions specifically address their needs and the reason for their admission.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	2.1. What is the appropriate community-based (including residential care) service capacity for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 2.2. What is the appropriate inpatient bed capacity (local and out of area) for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.1. What models of service delivery are effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.3. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different models of service delivery?

Quality of evidence	The evidence for these recommendations came from the review questions on the appropriate capacity for inpatient and community services, models of service delivery and the views and experiences of people who use services. We did not identify studies of high quality that compared the effectiveness or cost effectiveness of one model of service delivery over another. In the absence of direct evidence, the review team included studies that might provide some insights in to how the whole system currently works or does not work. The studies included views and experiences about the barriers and facilitators identified by people who use services and professionals, and process evaluations about implementation. There was little direct research evidence about the appropriate service capacity for inpatient or community services. In the absence of research evidence that directly answered these questions the review team presented evidence from studies that examined characteristics of service use, people's views and experiences to barriers and facilitators to access and take up of services and studies that reported on potentially negative outcomes such as out of area placements or delayed discharges associated with lack of provision of community services Recommendations 1.8.5, 1.8.6, 1.8.7 was supported by 4 evidence statements. Evidence statement AC10 on risk of out of area placements, from review question 2.2, was provided by 4 studies, 3 of low quality and 1 moderate quality. Evidence statement AC18 on shortages in inpatient capacity, from review question 2.2, was provided by 3 studies, 2 moderate quality and 1 low quality. Evidence statement SM31 on the impact of long stay hospital on family life, from review question 3.1, was provided by 1 moderate quality comparative study. Evidence statement SM32 on the impact of long stay hospital on community participation, from review question 3.3, was provided by 1 moderate quality comparative study and 1 low quality qualitative study. Recommendations 1.8.6 and 1.8.7 were also based on Guideline Committee consensus. Recommendation 1.8.8 was supported by 1 evidence statement AC6 on lack of specialist and crisis community services, from review question 2.1, which was provided by 4 studies: 2 moderate quality and 2 low quality.
Economic considerations	No relevant cost effectiveness evidence was identified for these recommendations. The Guideline Committee were mindful that recommendation 1.8.5 may have associated resource impact in terms of commissioning inpatient placements near to home, particularly in areas where there is a scarcity of provision. However, taken as a whole the guideline aims to reduce the use of inpatient placements. For recommendations 1.8.6, 1.8.7, the view of the committee was that this was something that should be part of the social work role anyway, but was not always happening in practice.
Evidence statements –	These recommendations are supported by: AC6 (recommendation 1.8.8)

numbered evidence statements from which the recommendations were developed	AC10 (recommendation 1.8.5, 1.8.6, 1.8.7) AC18 (recommendation 1.8.5, 1.8.6, 1.8.7) SM31 (recommendation 1.8.5, 1.8.6, 1.8.7) SM32 (recommendations 1.8.5, 1.8.6, 1.8.7)
Other considerations	Recommendations 1.8.5 and 1.8.6 were supported by evidence statements AC10, AC18, SM31 and SM32. This included evidence about groups at risk of out of area placements AC10, the relationship between lack of capacity and out of area placements AC18, and evidence that family and social contact can be more difficult to maintain in an inpatient setting compared to in the community, SM31 and SM32. The committee discussed the importance of people maintaining family and other social contacts while they are in hospital. 1.8.5 and 1.8.6 also addressed the needs of people with different ethnicity, religion or beliefs (a group highlighted through the Equality Impact Assessment). Recommendations 1.8.5, 1.8.6 and 1.8.7 were consensus recommendations based on the professional and personal experience of Guideline Committee members. The view of the committee was that it was important for the person to maintain contact with their social worker or name worker in the community as a way of facilitating discharge, by keeping them in touch with community services. It was the view of the committee that this should be happening anyway, and so would not result in particular additional resource. Following stakeholder feedback, the job title of the named worker was broadened out from the example of only the social worker, and in line with other NICE guidelines revised to read that this role could be assigned to an existing member of the person's support team, rather than requiring employment of new staff. Recommendation 1.8.8 was based on evidence statement AC6 which found that lack of community capacity could result in inpatient admissions. This recommendation therefore aimed to highlight that people who are in hospital should only remain there in order to receive interventions and treatment – not because there is no suitable community provision. The committee acknowledged that meeting this recommendation would require some areas to increase capacity in community services, which had a potential resource implication. However, the view of the committee was that improving community provision to reduce use of inpatient services is a key part of Transforming Care and Building the Right Support, and so local authorities should already be undertaking these changes as part of implementing this agenda.

Topic/section heading	**Planning and review to support discharge**
Recommendations	Recommendations for inpatient services and community learning disability teams

	1.8.9 As soon as the person is admitted, the hospital and community learning disability team should work together to develop a discharge plan. 1.8.10 Practitioners involved in the child, young person or adult's care and support should review the person's discharge plan at least every 3 months. Include in these reviews: - the person and their family members or carers - the practitioner responsible for agreeing discharge - a specialist in behaviour that challenges. 1.8.11 Think about using the Care and treatment review process or Care programme approach as a framework for reviews to support discharge for adults. For children and young people think about using the Care, education and treatment review or education, health and care planning process. 1.8.12 If the person is not discharged after the meeting with practitioners involved in their care and support, provide sufficient reason for this and develop a new plan towards discharge. Explain to the person and their family or carers how they can challenge the decision if they want to. 1.8.13 Tell people who might apply to, or are referred for, a first-tier mental health tribunal relating to being an inpatient, about their right to request an independent clinician (in line with section 76 of the Mental Health Act 1983) to: - visit them at any reasonable time and examine them in private - inspect any records relating to their conditions and treatment.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	2.2. What is the appropriate inpatient bed capacity (local and out of area) for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers?
Quality of evidence	There was no direct research evidence about the appropriate service capacity for inpatient services. In the absence of research evidence that directly answered these questions the review team presented evidence from studies that examined characteristics of service use, people's views and experiences to barriers and facilitators to access and take up of services, and studies that reported on potentially negative outcomes such as out of area placements or delayed discharges associated with lack of provision of community services. Recommendations 1.8.9, 1.8.10, 1.8.11 and 1.8.12 were based on 1 evidence statement AC20 on planning for discharge, from review question 2.2, which comprised 3 studies, 1 moderate quality and 2 low quality and supported by evidence from expert witness testimony IP02 from a clinical psychiatrist and expert witness testimony DS08 from a case study of services in Devon.
Economic considerations	No relevant cost effectiveness evidence was identified for these recommendations.

	In developing recommendations 1.8.9 to 1.8.13 the Guideline Committee were mindful of resource implications, aiming to ground recommendations in existing procedures and provision rather than introducing new requirements (see 'Other considerations' below).
Evidence statements – numbered evidence statements from which the recommendations were developed	These recommendations are supported by: AC20 (recommendations 1.8.9, 1.8.10, 1.8.11 and 1.8.12) DS08 (recommendation 1.8.9) IP02 (recommendation 1.8.9)
Other considerations	Recommendation 1.8.9 was based on evidence statement AC20 which related to the importance of care planning in inpatient units, including planning for discharge. It was supported by expert witness testimony from a clinician working in inpatient services who stated that planning for discharge should begin as soon as the person entered the inpatient setting. This was linked to the concept of a care pathway for people in inpatient settings, which was identified in two studies (Buxton et al 2004-, Devapriam et al. 2014-) and supported by expert witness testimony IP02 that current legal frameworks did not support smooth transition between services. The Devon Case study expert witness testimony DS08 also said that in their experience inpatient services are only effective when they are provided for a short period of time and are treatment focused and were very clear about the route to discharge Recommendations 1.8.10 and 1.8.11 were based on the same evidence and related to regular review of the care plan to facilitate discharge. The committee discussed how this regular review could be made meaningful, and focused on discharge, and be distinguished from a more routine ‘ward round’. The attendance of someone who would be able to ‘sign off’ discharge was thought to be key in achieving this. The committee considered existing structures that could be used for this discussion, and thought that Care Programme Approach meetings could be used where these applied, and would not require additional resource. For children and young people, the committee thought that the Care, Education and Treatment Review process could support these discussions, and again would not require additional resource. It was the view of the committee that a specialist in behaviour that challenges should be one of the attendees at the review meeting. Recommendation 1.8.12 was based on the same evidence and again related to mechanisms for facilitating discharge. The view of the committee was that, if discharge was not agreed, there should remain a focus on how that person could be discharged in the near future, and the support they would need. In particular, the committee thought it was important that people with learning disabilities and challenging behaviour and their families and carers were aware of local processes for challenging the outcomes of review meetings.

	Recommendation 1.8.13 was based on Guideline Committee consensus. It was the view of the committee that the involvement of an independent clinician can help to ensure discharge via the first-tier mental health tribunal process. The committee noted that this is something that people already have a right to under the Mental Health Act 2005. The recommendation therefore focuses on ensuring that people are aware of their right to this.

Topic/section heading	**Staff skills and values**
Recommendations	Recommendations for commissioners, local authorities and service providers 1.9.1 As part of staff recruitment and training, ensure that staff have the skills, knowledge and qualities they need to support the children, young people and adults they are working with. This includes: • the skills and knowledge recommended in staff training, supervision and support in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions. • being resilient and compassionate • showing that they care • understanding and respecting the person's human rights, faith, culture, identity and values. 1.9.2 Ensure that staff providing direct support to children, young people and adults with a learning disability and behaviour that challenges have the 'direct contact' level competencies of the Positive Behavioural Support Academy's Positive behaviour support competence framework. 1.9.3 Give staff providing direct support access to advice from behaviour support specialists with 'consultant' level competencies of the Positive Behavioural Support Academy's Positive behaviour support competence framework. 1.9.4 Local authorities and clinical commissioning groups should plan for and resource training among service providers who provide day-to-day support about how to work with young people and adults with a learning disability who are at risk of offending.
Research recommendations	What skills and competencies deliver the best outcomes for people with behaviour that challenges? What skills and competencies do staff need to meet forensic needs on the community? How many people are required with what skills in general and specialist services? What interventions are effective in supporting families, carers and staff to be resilient and able to provide care and support to people with a learning disability and behaviour that challenges?
Review questions	2.1. What is the appropriate community-based (including residential care) service capacity for children, young people and

	adults with learning disabilities and behaviour that challenges, and their families and carers? 3.1. What models of service delivery are effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.2. What models of service delivery are cost effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.3. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different models of services delivery?
Quality of evidence	The evidence for these recommendations came from the review of evidence on community capacity and models of service delivery. For both questions, there was little direct evidence to answer the review question. The reviews therefore included sources of evidence that might provide insights in to how the system works or does not work. This included evidence on views and experiences about barriers and facilitators identified by people who use services and professionals, and process evaluations about implementation, including evidence relating to staff knowledge and skills. The evidence available often highlighted deficits in staff knowledge and skills. The Guideline Committee therefore also used their own practice and personal knowledge to formulate a recommendation about what skills people should have and how this should be achieved. The evidence for recommendations 1.9.1 to 1.9.3 came from review questions 3.1 and 3.3 relating to models of service delivery. The recommendations were based on 4 evidence statements. Evidence in evidence statement SM7 that professionals need to understand behaviour that challenges was provided by 3 low quality studies. Evidence in evidence statement SM15 that staff do not always have the right knowledge, skills and qualities was provided by 3 moderate quality qualitative studies, 1 high quality study and 1 high quality systematic review. Evidence statement SM16 on what helps make sure staff have the right skills and attitudes was provided by 2 moderate quality studies and 1 high quality systematic review. Evidence SM26 about joint working was provided by 2 moderate quality studies. Recommendation 1.9.1 was further supported by expert witness testimony HPBS06 from Halton Borough council who run a Positive Behaviour Service and a Devon Case study DS03 The evidence for recommendation 1.9.4 came from review question 2.1 and was based on 1 evidence statement AC13 on sexual related behaviour and was provided by 1 moderate quality and 2 poor quality studies. This evidence highlighted the prevalence of sexual-related behaviour within offending behaviour by people with learning disabilities and behaviour that challenges. The Guideline Committee supplemented this evidence with their own practice knowledge about lack of skills in relation to offending behaviour more generally amongst staff providing day to day support.

Economic considerations	There was no cost-effectiveness research relating to these recommendations. The resource implications of training staff will depend on the type of training provided. Training is an investment, and if effective, training has the potential to provide the right care to match individuals' needs, leading to better outcomes and more efficient use of resources.
Evidence statements – numbered evidence statements from which the recommendations were developed	AC13 (recommendation 1.9.4) DS03 (recommendation 1.9.1) HPBS06 (recommendation 1.9.1) SM7 (recommendation 1.9.1, 1.9.2, 1.9.3) SM15 (recommendation 1.9.1, 1.9.2, 1.9.3) SM16 (recommendation 1.9.1, 1.9.2, 1.9.3) SM26 (recommendation 1.9.1, 1.9.2, 1.9.3)
Other considerations	Recommendations 1.9.1, 1.9.2 and 1.9.3 were based on evidence statements SM7, SM15, SM16, and SM26. This included evidence in evidence statement SM7 that professionals need to understand behaviour that challenges, evidence in SM15 that staff do not always have the right knowledge, skills and qualities to provide good care, evidence SM16 on what helps make sure staff have the right skills and attitudes and evidence SM26 that 'joint working' was important for the behavioural support team working well. The Guideline Committee discussed the challenges in recruiting and retaining staff. The Guideline Committee said that in their experience temporary staff were employed to fill the gap, and lacked the skills, experience, and commitment that were needed. Recommendation 1.9.1 also addressed the needs of people with different ethnicity, religion or beliefs (a group highlighted through the Equality Impact Assessment). The Guideline Committee also considered witness expert testimony HPB06 from Halton Borough Council, which provides a positive behavioural support service. They said that key parts of the service that worked well to support staff were that staff provided out of hours support for families, were skilled in positive behaviour support, and worked across settings providing training in positive behavioural support to ensure consistency in the standard of care. The Guideline Committee said it was very important that out of hours provision is staffed by people who knew about behaviour that challenges because people who may be experiencing crisis need highly specialised assessment and response. The Guideline Committee noted that all staff working with people should have the skills and competencies to deal effectively with behaviour that challenges. The current Positive Behaviour Support competence framework produced by the Positive Behaviour Coalition could be referred to for the level of competencies expected from different staff in all settings, who work with people with learning disabilities and behaviour that challenges. This was further supported by expert witness testimony DS03 from the Devon Case study that said they believed the service model worked well if staff were chosen to work with someone when they have the right temperament, values and shared interests and hobbies that will help that person develop and grow.

	Recommendation 1.9.4 was based on evidence statement AC13 which was about the prevalence of sexual related behaviour that maybe described a behaviour that challenges and the related service need for this group. The Guideline Committee noted that for early intervention in this area, staff who provide day to day support need to have training to recognise risky behaviour early and know when to refer to more specialised forensic services. Commissioners should make provision for training in this area for day to day support staff. 1.9.4 also addressed the needs of people in contact with the criminal justice system (a group highlighted through the Equality Impact Assessment).

Topic/section heading	**Staff skills and values**
Recommendations	1.9.5 Organisations should ensure that staff have supervision and support, in line with the recommendations on staff training, supervision and support in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions. 1.9.6 Involve young people and adults with a learning disability and behaviour that challenges in staff recruitment. Involve their family members and carers too if the person agrees, unless there is a compelling reason not to. 1.9.7 Think about how to involve children with a learning disability in staff recruitment.
Research recommendations	What skills and competencies deliver the best outcomes for people with behaviour that challenges? What skills and competencies do staff need to meet forensic needs on the community? How many people are required with what skills in general and specialist services? What interventions are effective in supporting families, carers and staff to be resilient and able to provide care and support to people with a learning disability and behaviour that challenges?
Review questions	2.1. What is the appropriate community-based (including residential care) service capacity for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.1. What models of service delivery are effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? 3.3. What are the views and experiences of children, young people and adults with learning disabilities and behaviour that challenges, their families and carers of different models of services delivery?
Quality of evidence	The evidence for these recommendations came from the reviews of evidence on models of service delivery. For all of these questions, there was little direct evidence to answer the review question. The reviews therefore included sources of evidence that might provide insights in to how the system works or does not work. This included evidence on views and experiences about

	barriers and facilitators identified by people who use services and professionals, and process evaluations about implementation, including evidence relating to staff knowledge and skills. The evidence for recommendation 1.9.5 came from review questions 3.1 and 3.3, and was based on 3 evidence statements. Evidence in SM15 that staff do not always have the right knowledge, skills and qualities to provide good care was based on 5 studies: 3 moderate quality studies, 1 high quality study and 1 high quality systematic review. Evidence statement SM16 was about what helps make sure staff have the right skills and attitudes and was based on 2 moderate quality studies and 1 high quality systematic review. Evidence statement SM30 found that better quality social care increases staff satisfaction and was based on 1 high quality randomised controlled trial. The evidence available often highlighted deficits in staff knowledge and skills. The Guideline Committee therefore also used their own practice and personal knowledge to formulate a recommendation about what skills people should have and how this should be achieved. The evidence for recommendations 1.9.6 and 1.9.7 came from review question 3.3 and was based on evidence statement SM16, based on 2 moderate quality studies and 1 high quality systematic review. Again, this highlighted some of the difficulties in recruiting and retaining staff. The solution in the recommendation was based on the professional and personal experience of the Guideline Committee.
Economic considerations	There was no cost-effectiveness research relating to these recommendations. However, increased investment in training and supporting staff is likely to lead to longer term savings in staff retention and preventing placement breakdown. The evidence on supporting placements also indicated that increased investment in supporting staff would be cost effective in the longer term by preventing placement breakdown and increasing staff retention.
Evidence statements – numbered evidence statements from which the recommendations were developed	SM15 (recommendations 1.9.5) SM16 (recommendations 1.9.5, 1.9.6 and 1.9.7) SM30 (recommendations 1.9.5)
Other considerations	Recommendation 1.9.5 was based on evidence statements that found staff do not always have the right knowledge, skills and qualities to provide good care SM15, what helps make sure staff have the right skills and attitudes SM16 and that providing better quality care increases staff satisfaction SM30. The Guideline Committee discussed their experiences that staff pressures of recruitment and retention was a barrier to good care and a source of stress. The experts by experience in the Guideline Committee said that it was very important to them that staff should get to know the person by developing genuine two-way relationships - rather than operating in a “robotic” way. They considered the evidence of what increases staff satisfaction and the link with staff retention. It was felt that good training, supervision and support

	can help to ensure a good quality service for people with learning disabilities and challenging behaviour, as well as improve staff satisfaction. These arrangements were already described in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions. Recommendations 1.9.6 and 1.9.7 were based on evidence statement SM16 on what helps make sure staff have the right skills and attitudes. The Guideline Committee discussed the unique role that staff have in supporting people and their families. The committee discussed that in their practice and experience it can be useful to involve family members and other people important to the person in recruitment, and if the person can be involved themselves. The Guideline Committee noted that there was no evidence currently that indicated that values and attributes were somehow fixed and measurable in potential staff. However, it was also noted that Skills for Care is currently piloting a tool for values based recruitment. Results from the pilot were not available at the time, but does indicate the interest in developing methods and values based tools for recruitment that includes an assessment of personal traits suitable for the role.

4 Implementation: getting started

NICE has produced tools and resources to help you put this guideline into practice.

Some issues were highlighted that might need specific thought when implementing the recommendations. These were raised during the development of this guideline. They are:

- Children, young people and adults with learning disabilities and behaviour that challenges are likely to need both health and care services, and care across their lifespan. However, lack of integration across services, including children's and adults' services, can impact on the quality of care. Local authorities, working together with clinical commissioning groups, can help to ensure a more joined-up and person-centred approach to care by designating a single lead commissioner who is responsible for commissioning learning disability health, social care, and education services for both adults and children, including for people whose behaviour is described as challenging. Creating this role may involve a significant change in practice for some services.
- Families and carers often play a significant role in supporting people with learning disabilities and behaviour that challenges, but they can find it confusing and difficult to access the information, guidance and support that they need. Many families need training and support for their caring role from specialist services including positive behaviour support services. Families may also benefit from services such as peer support. Local authorities and health services should provide sufficient good information, advice, guidance and support services for families, including information on how to access the support available. A significant change in practice may be required in areas which do not currently provide comprehensive support for families.
- Developing good general and specialist community services is important for supporting people with learning disabilities and behaviour that challenges to live how and where they want, and to help ensure they do not need to be admitted to hospital or to residential placements away from home. Developing capacity in services and housing to support people in the community is likely to be a challenge in areas where resources are focused on inpatient care. Clear plans will need to be developed, agreed and put in place to make this change.

- Children, young people and adults with learning disabilities and challenging behaviour should not be admitted to inpatient units unless all other possibilities have been considered and exhausted. Similarly, children and young people should only be admitted to residential placements if all other possibilities have been considered. When people are admitted to hospital, or children and young people are placed in a residential placement, planning for them to return to the community or a less restrictive placement should begin immediately. The plan should be reviewed regularly. Where this is not current practice, significant change will be required.

Putting recommendations into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes should be implemented as soon as possible, unless there is a good reason for not doing so (for example, if it would be better value for money if a package of recommendations were all implemented at once).

Different organisations may need different approaches to implementation, depending on their size and function. Sometimes individual practitioners may be able to respond to recommendations to improve their practice more quickly than large organisations.

Here are some pointers to help organisations put NICE guidelines into practice:

1. Raise awareness through routine communication channels, such as email or newsletters, regular meetings, internal staff briefings and other communications with all relevant partner organisations. Identify things staff can include in their own practice straight away.

2. Identify a lead with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally.

3. Carry out a baseline assessment against the recommendations to find out whether there are gaps in current service provision.

4. Think about what data you need to measure improvement and plan how you will collect it. You may want to work with other health and social care organisations and specialist groups to compare current practice with the recommendations. This may also help identify local issues that will slow or prevent implementation.

5. Develop an action plan, with the steps needed to put the guideline into practice, and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases.

6. For very big changes include milestones and a business case, which will set out additional costs, savings and possible areas for disinvestment. A small project group could develop the action plan. The group might include the guideline champion, a senior organisational sponsor, staff involved in the associated services, finance and information professionals.

7. Implement the action plan with oversight from the lead and the project group. Big projects may also need project management support.

8. Review and monitor how well the guideline is being implemented through the project group. Share progress with those involved in making improvements, as well as relevant boards and local partners.

NICE provides a comprehensive programme of support and resources to maximise uptake and use of evidence and guidance. See our into practice pages for more information.

Also see Leng G, Moore V, Abraham S, editors (2014) Achieving high quality care – practical experience from NICE. Chichester: Wiley.

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6 Related NICE guidance

To find out what NICE has said on topics related to this guideline, see our web pages on

Service user experience in adult mental health services NICE Quality Standard QS14 (2011)

Patient experience in adult NHS services NICE Quality Standard QS15 (2012)

Dementia: independence and wellbeing NICE Quality Standard QS30 (2013)

Autism NICE Quality Standard QS51 (2014)

Learning disabilities and behaviour that challenges NICE Quality Standard QS101 (2015)

Service user experience in adult mental health NICE guideline CG136 (2011)

Patient experience in adult NHS services NICE guideline CG138 (2012)

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges NICE guideline NG11 (2015)

Violence and aggression: short-term management in mental health, health and community settings NICE guideline NG10 (2015)

Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes NICE guideline NG5 (2015)

Transition between inpatient hospital settings and community or care home settings for adults with social care needs NICE guideline NG27 (2015)

Transition between inpatient hospital settings and community or care home settings for adults with social care needs NICE Quality Standard QS136 (2016)

Transition from children's to adult's services for young people using health or social care services NICE guideline NG43 (2016)

Transition from children’s to adults’ services NICE Quality Standard QS140 (2016)

Transition between inpatient mental health settings and community and care home settings NICE guideline NG53 (2016)

Mental health problems in people with learning disabilities NICE guideline NG54 (2016)

Autism: the management and support of children and young people on the autism spectrum NICE guideline CG142 (2016)

Learning disabilities: identifying and managing mental health problems NICE Quality Standard QS142 (2017)

7 Contributors and declarations of interests

Members of the Committee and other contributors to the guideline declared any relevant interests in line with the conflicts of interest policy.

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Declarations of interests

The following members of the Guideline Development Group made declarations of interest. All other members of the Group stated that they had no interests to declare.

Name	Declarations of Interest, date declared (recruitment / committee meeting)	Type of interest	Decision taken
Alix Lewer	Member of the Executive Committee of East Surrey Mencap and recently made an accessible questionnaire for them which aims to gather information about whether cuts to benefits or social care provision are affecting quality of life or increasing risks for of people with learning disabilities (some of whom have behaviour which challenges) (Declared at GC 9 – 09/03/17)	Personal non-financial (specific)	Declared and participated
Andrea Wiggins	Currently works for a provider who provides congregate and non-congregate settings for people with learning disabilities (GC 4 – 01/06/16)	Non-personal financial (specific)	Declared and participated
Andrea Wiggins	Co-authored papers included in the review at GC 6 (Declared at GC 6 – 03/10/16)	Personal non-financial (specific)	Declared and did not participate in any discussions or in writing any recommendations related to the specific evidence statement
Gary Bye (Feb 2016 – Sep 2017)	Trustee and Director of Association for Real Change, a charity supporting providers of services to people with a learning disability (Declared at recruitment)	Non-personal financial (non-specific)	Declared and participated
Isaac Samuels	People's Committee UEL (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated

Isaac Samuels	Member of research group City University (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Isaac Samuels	Redbridge Rainbow committee member (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Isaac Samuels	National co-production advisory group member SCI/TLAP (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Isaac Samuels	Blogger and guest writer Baseline magazine (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Isaac Samuels	Health watch member (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Isaac Samuels	Freelance consultant (sexual health, mental ill health, co-production and choice and control, equity diversity) (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Isaac Samuels	Peoples panel Expo- NHS 2015 (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Isaac Samuels	Newham council employment task group member (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Isaac Samuels	Newham council coproduction member (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Isaac Samuels	LGA -Peer Reviewer (Commission of better outcomes) (Recruitment)	Personal non-financial (non-specific)	Declared and participated
Isaac Samuels	Part of the IPC Programme Board (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated

Jeremy Winter	Author of an article in a book on 'Interprofessional Supervision' (Declared at recruitment)	Personal financial (non-specific)	Declared and participated
John Devapriam	Independent regulator of health and social care services at the Care Quality Commission (Declared at recruitment)	Non-personal financial (non-specific)	Declared and participated
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John Devapriam	Co-authored papers included in review at GC 5 (Declared at GC 5 – 10/08/16)	Personal non-financial (specific)	Declared and did not participate in any discussions or in writing any recommendations related to the specific evidence statement
John Devapriam	Involved in the work by the Royal College of Psychiatry on developing a methodology in accrediting services. This has a link to the evidence which was reviewed at GC 8. (Declared at GC 8 – 25/01/17)	Personal non-financial (specific)	Declared and did not participate in any discussions or in writing any recommendations related to the specific evidence statement
Jonathan Senker	Chief Executive of VoiceAbility and Advocacy Experience (subsidiary company). They provide advocacy support to people with learning disabilities and challenging behaviour which is funded by local authorities, NHS, and private and voluntary providers. (Declared at recruitment)	Non-personal financial (specific)	Declared and reviewed at each meeting in relation to evidence on advocacy. Did not take part in discussions or in writing recommendations in relation to this topic area
Jonathan Senker	Trustee and Chair of Board for The Single Homes Project (SHP)	Personal non-financial (non-specific)	No action needed

	(Declared at recruitment)		
Jonathan Senker	Has a sister who uses learning disability services (Declared at recruitment)	Personal non-financial (specific)	Declared and participated
Jonathan Senker	Father is a Trustee for Brighton & East Sussex Cross-Roads (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Karin Fuchs	Attended stakeholder workshop as part of the new NHS England service model guideline (Declared at recruitment)	Non-personal financial (specific)	Declared and participated
Karin Fuchs	Member of the Advisory Group for Intensive support (NHS England, Transforming Care) (Declared at GC 5 – 10/08/16)	Personal non-financial (non-specific)	Declared and participated
Lisa Hopkins	Trustee for Autism Schools Trust (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Lisa Hopkins	Works for an organisation who provides services for people in congregate and non-congregate settings (Declared at GC 4 – 01/06/16)	Non-personal financial (specific)	Declared and participated
Lisa Hopkins	Co-authored papers included in the review at GC 6 (Declared at GC 6 – 03/10/16)	Personal non-financial (specific)	Declared and did not participate in any discussions or in writing any recommendations related to the specific evidence statement
Mark Harvey	Co-Chair of the Social Workers Network (Declared at GC 8 – 25/01/17)	Personal non-financial (non-specific)	Declared and participated
Naomi Sills	Co-authored papers included in the review at GC 6 (Declared at GC 6 – 03/10/16)	Personal non-financial (specific)	Declared and did not participate in any discussions or

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Pam Bebbington	Trustee of My Life My Choice (from Feb 2016 – Nov 2017)	Personal non-financial (non-specific)	Declared and participated
Pam Bebbington	Doing some voluntary work for the Care Quality Commission (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Pam Bebbington	Paid work as a consultant (Declared at GC 13 – 12/12/17)	Personal financial (non-specific)	Declared and participated
Paul Scarrott	Trustee of My Life My Choice (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Paul Scarrott	Doing some voluntary work for the Care Quality Commission (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Rafik Hamazia	Part of the Secure Care Community Service Model Working Group as a Consultant (chaired by NHS England) (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Rafik Hamazia	Member of the Expert Reference Group Consultant for recommendations for Southern Health Foundation Trust (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Richard Hastings	Wife is a Cognitive Behaviour Therapist in a CAMHS service (NHS in Wales) (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Richard Hastings	Employed by University of Warwick. University receives funding under a research grant from NIHR (SSCR) to evaluate a brief staff training intervention focused on empathy towards people with challenging behaviour	Non-personal financial (specific)	Declared and participated

	(Declared at recruitment)		
Richard Hastings	Currently undertaking research from NISCHR (Wales) to evaluate mindfulness based intervention for adults with learning disabilities with anger/aggression problems, and from the Sharland Foundation to support a UK research and practice network on behavioural intervention methods with children and adults with learning disability/autism (including Positive Behavioural Support) (Declared at recruitment)	Non-personal financial (specific)	Declared and participated
Richard Hastings	Lead member of UK Positive Behavioural Support Academy that produced a PBS competencies framework released under a Creative Commons license. Is also doing other work in relation to this, producing other resources based on this competencies framework. (Declared at recruitment)	Personal non-financial (specific)	Declared and participated
Richard Hastings	Research advisor to Brain in Hand, Ambitious about Autism, Sibs and Positive Behavioural Solutions Ltd (a social enterprise) (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Richard Hastings	Committee membership: NICE Guideline Development Group for the Mental Health and Learning Disabilities (2014-2016); Skills for Health Learning Disabilities Core Skills Education and Training Framework Steering Group (2015-2016); NHS England Midlands and East Regional Transforming Care Board (2015-2016); Learning Disability Transforming Care Service Model Reference Group (NHS England, Local Government Association, ADASS), (2015); Chair of the Royal Mencap Society External Advisory Forum (2014 –); Mencap Cymru	Personal non-financial (specific)	Declared and participated

	Advisory Board (2015 -); Independent chair (appointed by NIHR HTA) of the Trial Steering Committee for an Epilepsy management in adults with learning disabilities RCT (PI H. Ring, Cambridge), (2014 – 2016); Independent chair (appointed by NIHR HS&DR) of the Study Steering Committee of the project “Mapping and evaluating Specialist Autism Team service models” (PI B. Beresford, York), (2014-2016); Trustee for the Royal Mencap Society (2009 - 2015) (Declared at recruitment)		
Richard Hastings	Co-authored the following papers which were included in the evidence review at GC 3: Griffith G M, and Hastings R P. (2014). ‘He's hard work, but he's worth it’. The experience of caregivers of individuals with intellectual disabilities and challenging behaviour: a meta-synthesis of qualitative research. Journal of Applied Research in Intellectual Disabilities, 27(5), pp.401-419. Griffith G M, Hutchinson Li, and Hastings R P. (2013). "I'm not a patient, I'm a person": The experiences of individuals with intellectual disabilities and challenging behavior – A thematic synthesis of qualitative studies. Clinical Psychology: Science and Practice, 20, pp.469-488. (Declared at GC 3 – 12/04/16)		Declared and did not participate in any discussions or in writing any recommendations related to the specific evidence statement
Rowena Tye	Member and Trustee of HF Trust which is a charity supporting adults with learning disabilities. Rowena’s son who has a learning disability is also supported by this charity.	Personal non-financial (specific)	Declared and participated

	(Declared at recruitment)		
Rowena Tye	Rowena's son uses congregate services (Declared at GC 4 – 01/06/16)	Personal non-financial (specific)	Declared and participated
Sharon Jeffreys	Member of the Expert Reference Group for Transforming Care (Declared at GC 9 – 09/03/17)	Personal non-financial (non-specific)	Declared and participated
Veronique Kaboha	Independent expert by experience working on care and treatment reviews (Declared at recruitment)	Personal financial (non-specific)	Declared and participated
Veronique Kaboha	Member of Lambeth Parents Forum (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Veronique Kaboha	Member of Parents Special Interest Group by UK Society for Behavioural Analysis (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Veronique Kaboha	Affiliate member of UK-SBA (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Veronique Kaboha	Written some articles about own personal experience and other parents' experience of working with Applied Behaviour Analysis which have been published by the campaign ABAaccess4ALL (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Veronique Kaboha	Commented on posts on the ABAaccess4ALL Facebook campaign page (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Veronique Kaboha	Runs a campaign to improve autism education locally - The Hub Lambeth (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Veronique Kaboha	Has given talks in the last year about own personal experience of being a parent of a child with learning disability and challenging	Personal non-financial (specific)	Declared and participated

	behaviour to the following organisations: NHS England, North West London NHS and Kingston University (Declared at recruitment)		
Veronique Kaboha	Member of the London Learning Disability Workforce Network organised by the Health Education England London offices. (Declared at recruitment)	Personal non-financial (specific)	Declared and participated
Veronique Kaboha	Member of Focus South London (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Vivien Cooper	Trustee, Co-founder and Chief Executive of The Challenging Behaviour Foundation (CBF) (Declared at recruitment)	Personal financial (specific)	Declared and participated
Vivien Cooper	Member of the NICE Quality Standards Advisory Committee for Challenging behaviour and learning disabilities (Declared at recruitment)	Personal non-financial (specific)	Declared and participated
Vivien Cooper	Member of the Transforming Care Assurance Board (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Vivien Cooper	Member of the Learning Disability Medicines Oversight Group (Declared at recruitment)	Personal non-financial (specific)	Declared and participated
Vivien Cooper	Member of the Learning Disabilities Change and Improvement Steering Group (Declared at recruitment)	Personal non-financial (specific)	Declared and participated
Vivien Cooper	Member of the CQC Learning Disabilities Advisory Group (Declared at recruitment)	Personal non-financial (specific)	Declared and participated
Vivien Cooper	Member of the Hassiotis UCL PBS Research Group	Personal non-financial (non-specific)	Declared and participated

	(Declared at recruitment)		
Vivien Cooper	Member of the Tizard E-Pats Fellowship Steering Group (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Vivien Cooper	Member of the CDC Restrictive Physical Intervention Steering Group (Declared at recruitment)	Personal non-financial (non-specific)	Declared and participated
Vivien Cooper	The Challenging Behaviour Foundation wrote one of the papers which was reviewed at GC 7 Declared at GC 7 – 22/11/16)	Personal non-financial (specific)	Declared and did not participate in any discussions or in writing any recommendations related to the specific evidence statement
Vivien Cooper	CBF's involvement in the Channel 4 Dispatches documentary 'Under lock and key' – provided information to Ch4, supported two of the families featured in the documentary and also attended a roundtable discussion at Channel 4 (Declared at GC9 – 09/03/17)	Personal non-financial (specific)	Declared and participated
Vivien Cooper	Provided evidence to the National Audit Office and attended meetings with their team (Declared at GC9 – 09/03/17)	Personal non-financial (non-specific)	Declared and participated
Vivien Cooper	Issued a joint statement with Mencap about the NAO report (Declared at GC9 – 09/03/17)	Personal non-financial (non-specific)	Declared and participated
Vivien Cooper	Given evidence at the Public Accounts Committee (Declared at GC9 – 09/03/17)	Personal non-financial (non-specific)	Declared and participated
Vivien Cooper	Submitted evidence to the Calderstones closure consultation, and to the Lenehan review about residential schools for children with learning	Personal non-financial (specific)	Declared and participated

	disabilities who display behaviour described as challenging (Declared at GC9 – 09/03/17)		
Vivien Cooper	Attended the Transforming Care Children and Young People group (Declared at GC9 – 09/03/17)	Personal non-financial (non-specific)	Declared and participated
Vivien Cooper	Submitted evidence to the CAMHS service specification consultation (Declared at GC9 – 09/03/17)	Personal non-financial (non-specific)	Declared and participated
Vivien Cooper	Member of the expert reference group of the Building the Right Support Evaluation (Declared at GC9 – 09/03/17)	Personal non-financial (non-specific)	Declared and participated

8 Glossary and abbreviations

Glossary

Cohen’s D

Cohen’s D is one of the most common ways to measure effect size. An effect size is how large an effect of something is. For example, independent living has a better effect than group housing.

Congregate housing

A type of housing in which each person has a private bedroom or living quarters but shares with other residents a common dining room, recreational room, or other facilities. In the context of this review, it also means that most of the people living together are people with learning disabilities and behaviour that challenges

EPPI Reviewer

Specialist reference management software used for all types of literature and research reviews, including systematic reviews, meta-analyses and 'narrative' reviews, developed and provided by the Evidence for Policy and Practice Information (EPPI) Centre.

Non congregate housing

In the context of this review it means that most people living in the home did not have learning disabilities and behaviour that challenges.

Gillick competent

Gillick competence is a legal term concerned with determining a child’s capacity to consent. If a child passes the Gillick test, he or she is considered ‘Gillick competent’ to consent to that medical treatment or intervention. If a child does not pass the Gillick test, then the consent of a person with parental responsibility (or sometimes the courts) is needed in order to proceed with treatment.

Real tenancy test

The Real tenancy test is a quick test to check that a person who lives in supported accommodation enjoys the same rights and protections in law as a person who has a full tenancy agreement for their rented home.

Residential placement

Examples of residential placements include residential care homes for adults and, for children and young people, placements that involve living away from their family home such as residential schools and colleges.

Semi-independent living

Is a type of supported accommodation which is usually defined as having no paid staff support for at least 28 hours per week.

Shared Lives

A type of supported accommodation scheme. It is where someone with care and support needs moves in with a Shared Lives carer as part of a supportive household. This means the owner or landlord of the property provides some care or support.

Please see the NICE glossary for an explanation of terms not described above.

Abbreviations

Abbreviation	**Term**
ABC	Aberrant Behavior Checklist
ABS	Adaptive Behavior Scale
AOT	Assertive outreach team
ASD	Autism spectrum disorders
BCATS	Birmingham Community Assessment and Treatment Service
BST	Behavioural support team
CAMHS	Child and adolescent mental health service
CBC	Challenging Behaviour Checklist
CFT	Community forensic learning disability team
CJS	Criminal justice system
CLTD	Community learning disability team
CNLD	Community nurse for people with learning disabilities
CSRI	Client Services Receipt Index
CSRI-CID	Client Service Receipt Inventory for Children with Intellectual Disabilities

CTR	Care and Treatment Reviews
EHCP	Education health and care plan
FRS	Flexible response service
FSTP	Fire-setter treatment programmes
GP	General practitioner
HoNOS-LD	Health of the Nation Outcome Scales for People with Learning Disabilities
HSCIC	Health and Social Care Information Centre
HSS	Health and social services
ICAP	Inventory for Client and Agency Planning
ID	Intellectual disability
LD	Learning disability
MHA	Mental Health Act 1983
MHP	Mental health problems
NAAPS	National Association of Adult Placement Services
NDTI	National Development Team for Inclusion
OAP	Out-of-area placement
OT	Occupational therapist
PAS-ADD	Psychiatric Assessment Schedule for Adults with a Developmental Disability
PBS	Positive behaviour support
PBSS	Positive behavioural support services
PCP	Personal care plan
PDD	Pervasive developmental disorder
PSSRU	Personal Social Services Research Unit
QOL	Quality of life
RQ	Review question
sd	Standard deviation
SDQ	Strengths and Difficulties Questionnaire
SLOT	Supported living outreach team
SPR	Single point of referral
SPSS	Statistical Package for the Social Sciences

About this guideline

What does this guideline cover?

The Department of Health (DH) asked the National Institute for Health and Care Excellence (NICE) to produce this guideline on Learning disabilities and behaviour that challenges: service design and delivery (see the scope).

The recommendations are based on the best available evidence. They were developed by the Guideline Committee – for membership see section 7.

For information on how NICE social care guidelines are developed, see Developing NICE guidelines: the manual.

Other information

We have developed a pathway and information for the public and tools to help organisations put this guideline into practice. They are available on our website.

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