NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

DRAFT GUIDELINE

Care and support of older people with learning disabilities

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Introduction

The Department of Health asked NICE to produce this guideline on Care and support of older people with learning disabilities (see the scope).

They will have many of the same age-related health and social care needs as other older people but they also face specific challenges associated with their learning disability. Many older people with learning disabilities, especially those with milder disability, are not known to health or social services (People with learning disabilities in England 2013, Public Health England 2014), while others may find it difficult, because of their learning disability, to express their needs and be heard. Management of their needs will therefore be more complex than for other populations. This will create substantial pressure on services which has not yet been fully quantified.

Health and social issues of older people with learning disabilities

People with learning disabilities have a poorer health profile than the general population. For example, there is a high prevalence of dementia in people with Down’s syndrome. Practitioners may have difficulty distinguishing the symptoms of a condition such as dementia from those associated with learning disabilities and other mental health difficulties.

People with learning disabilities may have increased risk of mortality due to conditions associated with their learning disability (e.g. epilepsy, aspiration pneumonia). However, many such conditions are often diagnosed late in the course of illness. The Michael Report: Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities (2008) and the subsequent Confidential Enquiry into Premature Deaths of People with Learning Disabilities (CIPOLD, Heslop et al. 2013) identified a failure of services to take account of the needs of people with learning disabilities and make reasonable adjustments. This led to misdiagnosis and in some instances premature death.

Adults with a learning disability are far more likely to have sensory impairment compared to the general population, but are less likely to access sight, hearing or dental checks, particularly if they are living independently or with family. Sensory impairment is also a barrier to accessing services.

Older people with learning disabilities also experience particular housing and social support needs. Two thirds of adults with learning disabilities live with their families, usually their parents. In some instances the person with a learning disability may be caring for an aged frail parent whilst they themselves are getting older. The health of the older person with a learning disability as well as chronic behaviours that challenge may lead ageing family carers to reluctantly explore alternative care arrangements. More problematic is when family care ends through parental illness or death and, due to lack of future planning, the individual is moved inappropriately.

For those living in homes designed for adults with learning disabilities, these may be considered unsuitable for them as they age, which can lead to a move. Older people with learning disabilities are thus more likely to be placed in older people's residential services at a much younger age than the general population, even though this may not meet their preferences or needs, especially in regard to communication and support.

The purpose of this guideline

The purpose of this guideline is to help commissioners and providers identify, plan and provide for the health and social care needs of older people with learning disabilities and their families and their carers. It covers integrated commissioning and planning; service delivery and organisation; providing accessible information, advice and support; identifying and assessing people's changing needs, care planning, and providing and supporting access to services including health, social care, housing and end of life care. It aims to ensure that older people with learning disabilities are given the help they need to access a range of services as they reach old age so they can live healthy and fulfilled lives.

The guideline covers care and support for older people with learning disabilities in all settings, including:

- people’s homes, including family homes, temporary accommodation, supported living (including Key Ring Network and Shared Lives Schemes) and specialist accommodation.

It also covers:

- day services, residential and nursing homes and
- primary and secondary healthcare.

A specific age limit is not used in this guideline because adults with learning disabilities typically experience age-related difficulties at different ages, and at a younger age than the general population. The guideline does not cover older people on the autistic spectrum who do not have a learning disability.

We used the methods and processes in Developing NICE guidelines: the manual (2014).

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 safeguarding.

1.1 Overarching principles

Access to services and person-centred care

1.1.1 Ensure older people with learning disabilities have the same access to care and support as everyone else, based on their needs and irrespective of:

- age
- disability
- gender reassignment
- marriage and civil partnership
- pregnancy and maternity
- race, religion and belief
- sex and sexual orientation
- socioeconomic status
- other aspects of their identity.

[This recommendation is adapted from the NICE guideline on service user experience in adult mental health.]

1.1.2 Give older people with learning disabilities care and support that is tailored to their needs, strengths and preferences and is not determined solely by their age or learning disability.

1.1.3 Service providers and commissioners must make reasonable adjustments to health, social care and housing services to ensure they are fully accessible to older people with learning disabilities and their family members and carers, in line with the Equality Act 2010.

1.1.4 Recognise that older people with learning disabilities may be carers, but may not see themselves as such. Ask the person if they have caring responsibilities and, if so, offer them a carer's assessment to meet their needs[1].

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

Communicating and making information accessible

1.1.5 Practitioners must support people's communication needs and information preferences in line with NHS England's Accessible Information Standard. This includes:

- Finding out before an appointment how the person prefers to communicate and receive information.
- Extending appointment times to give more time for discussion.
- Giving people written information (such as appointment letters and reminders) in an accessible format of their choice, for example Easy Read, audio books, films or by using online resources such as specialist learning disability websites.
- Providing information on advocacy services and, if the person needs it and consents to it, providing an independent advocate who will attend appointments.
- Using visual aids and short, clear sentences during consultations and conversations.
- Talking to the person's family members and carers, if appropriate and with the person's consent.

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[1] NICE's guideline on provision of support for adult carers is in development and is due to be published in July 2019.

1.1.6 Give older people with learning disabilities and their family members and carers accessible information about:

- the range and role of different health services (such as health checks and screening)
- how to access health, social care and support services
- the community and specialist services that are available, and their purpose
- housing options that they could think about for the future.

1.1.7 Social care and primary care practitioners should regularly review the communication needs of people with learning disabilities as they grow older to find out if they have changed. This should usually be when:

- other needs are being assessed, for example during general health and dental checks
- there is reason to believe their communication needs may have changed.

Decision-making, mental capacity and consent

1.1.8 Assume that older people with learning disabilities have mental capacity to participate in planning and decision-making about their care and support unless it is established that they lack capacity, in line with the Mental Capacity Act 2005. Assess the person's capacity for each decision and carry out this assessment where and with whom the person wishes[2].

Involving people and their family members and carers

1.1.9 Health and social care practitioners should listen to, actively involve and value key members of the person's support network in the planning and delivery of their current and future care and support, if the person agrees to this. Regularly check people's willingness and ability to be involved in this way.

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[2] NICE's guideline on decision making and mental capacity is in development and is due to be published in May 2018. This guideline will cover supporting people to make decisions, assessing mental capacity and best interests decision-making.

1.1.10 Ask the person who they want to involve if they do not have close family members. Ensure they are aware of their right to an advocate and how to access this support.

1.1.11 Find out and prioritise the needs and preferences of the person. Ensure these are not overshadowed by the decisions or preferences of others, including when the person lacks capacity.

1.1.12 Be aware that older people with learning disabilities may need support to communicate their needs or retain information. With the person's consent, share information with their family members and carers, for example about:

- any changes that might be needed to their care and support
- symptoms, management and prognosis of the person's health conditions.

1.2 Organising and delivering services to help people live a good life

Planning and commissioning local services

1.2.1 Health and social care commissioners should have an understanding of the needs of older people with learning disabilities in their area and know what mainstream and specialist services are available locally to support people as they grow older.

1.2.2 Commissioners should identify the number of households that include an adult with a learning disability, and use this information to identify gaps in provision, organise services and plan future provision. This could be done by encouraging GPs to develop and maintain registers of people with learning disabilities and getting information from other support services, including education and the Department for Work and Pensions.

1.2.3 Commissioners and service providers should ensure family members, carers and advocates of older people with learning disabilities have age-appropriate community support services and resources such as:

- day opportunities
- short respite breaks (both at home and away from home)
- family placements
- support groups for family carers, including siblings, and for older people with learning disabilities who have caring responsibilities
- a single point of contact for practical information, emotional support and signposting.

1.2.4 Commissioners and service providers should provide housing options that meet the changing needs of people with learning disabilities as they grow older. This includes:

- making reasonable adjustments to accommodate their changing physical and emotional needs
- providing equipment or housing adaptations
- ensuring accessible transport links are available to help people access local facilities
- arranging housing for older people with learning disabilities who are in unstable housing situations, for example those who are homeless or in temporary accommodation (including people seeking asylum).

1.2.5 Commissioners should make available locally a wide range of housing, family and community support options to meet the needs of older people with learning disabilities, as they grow older, including people in later old age and their family members and carers. These might include:

- access to advocacy services
- respite care
- in-home support (such as physical adaptations)
- supported living

- residential and nursing care which reflect gender, sexual orientation and cultural preferences.

1.2.6 Consider the use of telehealth and telecare for older people with learning disabilities, their family members and carers, and relevant partners such as GPs and adult social care services.

1.2.7 Clinical commissioning groups should identify where there are gaps in community optometry and dental services for older people with learning disabilities and address those gaps.

1.2.8 Mental health commissioners should develop protocols to ensure that older people with learning disabilities, including people in later old age, have access to mainstream mental health services for older people, including dementia support.

1.2.9 Commissioners and service providers should ensure that older people with learning disabilities have equal access to a range of community services that reflect the cultural diversity of the local area and people’s hopes, preferences, choices and abilities as they grow older.

1.2.10 Commissioners and providers should establish links between specialist learning disability services and mainstream older people's services. This could be done by bringing them together to help identify gaps and inform service development, sharing information and learning, and linking into voluntary sector umbrella groups.

1.2.11 Commissioners and providers should provide opportunities for older people with learning disabilities to meet up and socialise, for instance through social clubs and support groups.

1.2.12 Commissioners and providers should ensure there is a wide range of community-based physical activity programmes available and encourage people to take part to promote their health and wellbeing. Examples include dancing, swimming, bowls, using the gym, organised walks and chair-based exercise classes.

1.2.13 Commissioners and providers should arrange accessible opportunities for older people with learning disabilities to engage in education, working and volunteering.

1.2.14 Local authorities should consider introducing schemes to make transport easier for older people with learning disabilities. For example:

- providing free travel such as London's 'Freedom pass'
- using minibuses as community transport
- starting 'buddy' schemes to enable independent travel
- developing transport especially for people living in rural locations
- schemes such as 'JAM' cards (Just A Minute) – which can be used to alert transport staff that people have a learning disability
- schemes to help people with a personal budget to travel to activities and self-advocacy groups.

1.3 Identifying and assessing care and support needs

Assessing people's need for care and support

1.3.1 Ensure that all assessments of care and support needs are person centred (NICE is publishing a guideline on people's experience in adult social care services in February 2018 which covers person-centred assessment).

1.3.2 Practitioners carrying out assessments of care and support needs should have:

- access to the person's full history (medical, social, psychological and the nature of their learning disability) and
- an understanding of their usual behaviour.

1.3.3 Practitioners carrying out assessments of care and support needs should be alert to any changes in the person's usual behaviour. This could include how they are communicating or their activity levels, and symptoms (such as weight loss, changes in sleeping patterns or low mood) that could show something is wrong or they are unwell.

1.3.4 When people have changing needs think about whether these changes could be age-related and do not assume they are due to the person's learning disability.

1.3.5 Practitioners conducting assessments of care and support needs should help people to think about what they want from life as they age. This should include:

- asking people how they would like to spend their time and with whom
- encouraging them to develop support networks and to build and maintain links with friends and family and with community groups – these might include social, cultural and faith-based groups.

Assessing the needs of family members and carers

1.3.6 Practitioners conducting assessments of care and support needs should take into account the needs, capabilities and wishes of families and carers. Also take into account that there may be mutual caring between older people with learning disabilities, and their family members and carers, who are likely to be older themselves and have their own support needs.

1.3.7 Practitioners must offer people who are caring for an older person with a learning disability their own carer's assessment, in line with the Care Act 2014.

1.3.8 Based on assessment, provide families and carers with support that meets their needs as carers.

1.3.9 Review the needs and circumstances of carers at least once a year and if something significant changes.

1.3.10 Actively encourage carers to register themselves as a carer, for example with their GP.

1.4 Planning and reviewing care and support

Person-centred planning and review

1.4.1 Practitioners should carry out regular person-centred planning with people who have a learning disability to address their changing needs, wants and capabilities. This includes planning for the future. Involve their family, carers and advocates as appropriate.

1.4.2 Include transport needs in people's care and support plans, to help them get to services, appointments and activities.

1.4.3 Local authorities should plan people's care and support in a way that meets the needs of all family members, as well as the older person with a learning disability. This might include combining the personal budgets of different family members.

1.4.4 Give families and carers, including siblings, help in planning and providing support for the older person with a learning disability. For example, signposting people to resources about how to support people after a family bereavement.

Planning for the future

1.4.5 Health and social care practitioners should work with the person and those most involved in their support to agree a plan for the person's future. Help them to make decisions before a crisis point or life-changing event is reached (for example, the death of a parent or a move to new housing).

1.4.6 Planning for the future should:

- be proactive
- be led by the person themselves with input from family members, carers and advocates as appropriate (regardless of whether they provide care and support themselves)
- involve a practitioner who has a good relationship with the person and communicates well with them

- involve practitioners who have good knowledge of local resources
- take into account the whole of the person's life, including their hopes and dreams as well as the things they do not want to happen
- include considering the needs of family members and carers
- seek to maintain the person's current support and housing arrangements, if this is their preference
- be reviewed every year and whenever the person's needs or circumstances change.

1.4.7 Include as key components of a future plan:

- Housing needs and potential solutions.
- Any home adaptations or technology that may address people's changing needs as they grow older.
- Members of the person's support network (both paid and unpaid).
- Any help the person gives to other family members, whether this will continue as they age, and the impact this may have on their health and wellbeing.
- Financial and legal issues, for example whether someone has been appointed to have lasting power of attorney for the person.
- Planning for unexpected changes or emergencies
- Consideration of deprivation of liberty safeguards, for instance if planned changes to care or the care environment are likely to increase restrictions on the person.
- End of life care decisions – including where the person wants to be when they die. These decisions should be reviewed at least once a year.

Future housing

1.4.8 When helping the person plan where they will live in the future and who they will live with, take into account whether other family members rely on them for support.

1.4.9 Encourage and support people to be active and independent at home regardless of their age or disability. This might include doing household tasks, making their own decisions and plans or leading group activities.

1.4.10 Make reasonable adjustments to people's homes as they grow older to make it possible for them to stay in their current home if they want to. For example, consider a support phone line, daily living equipment, telehealth monitoring and home adaptations, such as shower room conversion, wider doorways or a lift between floors.

1.4.11 Review the housing needs of people who are being supported by social care staff at home at least once a year.

1.4.12 Ensure that an advocate or, if appropriate, a family member or carer is centrally involved in decisions about whether a person should move from supported living to residential care.

1.4.13 If a move into residential care is agreed with the person, practitioners should work with them and their support network to start planning for this straightaway. Planning could include:

- arranging for the person to visit the residential setting
- discussing how they will maintain their existing support networks and develop new ones.

1.5 Identifying and managing health needs

1.5.1 Healthcare practitioners should encourage older people with learning disabilities to choose a family member or carer to bring with them to medical examinations and appointments if they would like this support.

1.5.2 Explain clearly to older people with learning disabilities what will happen during any medical appointments as well as their likely follow-up care. In line with the Mental Capacity Act 2005, healthcare practitioners must take all reasonable steps to help the person understand this explanation.

1.5.3 As well as explaining to people beforehand what will happen, continue to explain what is happening throughout the appointment and ensure there is enough time set aside to do this. If the person agrees, also explain to their family members and carers what will happen.

1.5.4 If the person needs a medical examination give them a choice, wherever possible, about where it takes place. Aim to do it in a place that is familiar to them, which is welcoming and appropriate to their needs.

1.5.5 Support family members and carers, for example by providing information, to enable older people with learning disabilities to access health services.

1.5.6 Consider training for people and their family members and carers in recognising and managing age-related conditions such as:

- hearing loss and sight problems
- blood pressure and cholesterol
- prostate cancer
- epilepsy
- diabetes
- osteoporosis
- thyroid problems
- menopausal symptoms
- mental health, including depression and dementia.

Coordinating care and sharing information

1.5.7 Managers in healthcare settings should identify a single lead practitioner to be the point of contact for older people with learning disabilities and their family members and carers. This practitioner could be a member of the community learning disability team or a nurse with experience in learning disabilities.

1.5.8 Ensure that everyone involved in the person's care and support shares information and communicates regularly about the person's health and any treatment they are having, for example by holding regular multidisciplinary meetings. Involve the person in all discussions.

1.5.9 Primary and secondary healthcare teams should identify at least 1 member of staff who develops specific knowledge and skills in working with older people with learning disabilities and acts as a champion, modelling and sharing good practice. Use the expertise of older people with learning disabilities to ensure the champion understands their needs.

1.5.10 Record a person's learning disability in their health records. With the person's consent, make sure all healthcare practitioners in community and acute settings can access this. Also record any specific needs or wishes, for example to do with the person's communication or mobility.

Health checks and screening

1.5.11 Offer older people with learning disabilities the same routine screening and health checks as other older people.

1.5.12 Recognise that older people with learning disabilities may need additional health surveillance to help them identify and communicate symptoms of age-related conditions. This could include providing information about annual health checks including what they involve and how to arrange them.

1.5.13 Discuss with people changes that may occur with age. Ask them about and monitor them for symptoms of common age-related conditions, including:

- hearing loss and sight problems
- blood pressure and cholesterol
- prostate cancer
- epilepsy
- diabetes
- osteoporosis
- thyroid problems
- menopausal symptoms.
- mental health, including depression and dementia (also see recommendations 1.5.36 and 1.5.37).

1.5.14 If the person is having an annual health check, give them information about other available services, including a care and support assessment under the Care Act 2014 if they have not already had one.

1.5.15 If the person is having an annual health check, ask if they are registered with a dentist, how often they see the dentist and check that they understand the importance of looking after their teeth and mouth.

1.5.16 Give people clear, accessible and practical information and advice about keeping well as they grow older. Tell them about, and help them to access, preventative services such as breast screening, smear tests, testicular and prostate checks and dental checks.

1.5.17 When designing and delivering breast screening services, address specific barriers to accessing breast screening among older women with learning disabilities, including support to:

- understand breast cancer
- understand the screening procedure
- perform breast self-examination
- understand any information provided
- attend appointments.

Primary care

1.5.18 Design primary care and community services so that older people with learning disabilities can see the same GP and other healthcare practitioners, wherever possible, to help practitioners:

- become familiar with the person's medical history, which the person may have difficulty remembering themselves
- build good relationships and understand the person's usual behaviour and communication needs.

1.5.19 General practices should allocate a named member of staff to remind older people with learning disabilities about appointments for screening and health examinations. This staff member should help the person attend the appointment by:

- using each person's preferred method of communication
- giving them information in a way they can understand
- ensuring the person understands the reason for the appointment and why it is important
- finding out their transport needs
- making reasonable adjustments to help the person and their carer or supporter to attend.

1.5.20 If the person is diagnosed with a health condition give them, and their family members and carers, accessible information on the following (taking time to explain it to them as well):

- symptoms and management
- benefits, and potential side effects, of treatment
- how to take their prescribed medicines.

1.5.21 Support older people to manage their own health conditions by getting to know them and adapting health advice to suit their personal choices and the activities they already enjoy (for example, playing football).

Dental care

1.5.22 Commissioners and managers should ensure support staff have knowledge of oral health so they can support older people with learning disabilities to maintain good oral health and access dental services.

1.5.23 Dental practices should ensure their services are accessible to older people with learning disabilities, for example by:

- reminding people about their appointments by phone
- sending letters in an accessible format, for example Easy Read
- suggesting that the person brings a carer or supporter with them
- ensuring staff have the skills to communicate with people with learning disabilities and put them at ease.

1.5.24 For further guidance on managing oral health see the NICE guidelines on:

- oral health promotion: general dental practice
- oral health for adults in care homes.

Outpatient appointments

1.5.25 Hospitals should arrange for the person and a family member or carer to visit the hospital before their outpatient appointment to meet the staff who will conduct any tests or examinations, see the equipment that will be used and identify what adjustments will be needed.

Before and during a hospital stay

1.5.26 When planning a hospital admission, arrange a pre-admission planning meeting, including the hospital liaison team or liaison nurse, a representative of the community learning disability team, the person and their family members and carers. At this meeting:

- complete the pre-admission documentation, which should include information from the person's hospital passport
- discuss any reasonable adjustments needed, for example, arranging for the person to visit the hospital before their admission to meet the learning disability liaison nurse who will be their contact.

1.5.27 Hospitals should actively encourage staff to use pre-admission documents and flagging systems so that all relevant hospital staff know about the person's learning disability. At discharge, review how well this is working.

1.5.28 Hospitals should develop policies and guidance to enable someone chosen by the person to stay with them throughout their inpatient stay. This should include providing facilities for them to stay overnight.

1.5.29 Hospital staff should continue to offer health and personal care (toileting, washing, nutrition and hydration) to older people with learning disabilities even if they have a family member or carer there to support them.

1.5.30 For further guidance on planning admission and admitting adults with identified social care needs to hospital, see NICE's guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.

Transfer of care from hospital

1.5.31 Invite family members, carers or advocates to pre-discharge meetings, as well as the person themselves.

1.5.32 If the discharge plan involves support from family members or carers, take into account their:

- willingness and ability to provide support
- circumstances, needs and aspirations
- relationship with the person
- need for respite.

[This recommendation is adapted from the NICE guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.]

1.5.33 Give the person (and their family members and carers) an accessible copy of their discharge plan when they are discharged, and make sure their GP has a copy within 24 hours. Make sure everyone knows what will happen next in the person's care and support.

[This recommendation is adapted from the NICE guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.]

1.5.34 After the person is discharged, the hospital learning disability liaison nurse, community learning disability teams and primary care practitioners should work together to provide ongoing support to the person to help them manage their health conditions.

1.5.35 For further guidance on discharging adults with identified social care needs from hospital, see NICE's guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.

Care and support for people living with dementia

1.5.36 Explain at an early stage to older people with learning disabilities (particularly people with Down's syndrome) and their family members or carers about the link between learning disabilities and dementia. Explain the signs of dementia, how it usually progresses and what support is available. Give people:

- printed information on dementia
- opportunities for one-to-one discussion with a professional
- advice on communication strategies for people with dementia.

1.5.37 Commissioners should ensure information is provided to family members and carers of older people with learning disabilities who are being assessed for, or have been diagnosed with dementia. Consider also providing training. Information and training might cover:

- types of dementia
- how dementia might present in people with different learning disabilities
- care pathways for different dementias
- practical steps to manage daily life
- communication skills
- how to find further advice and ongoing support, including support groups and respite services.

1.6 End of life care

Access to end of life care services

1.6.1 Give older people with learning disabilities and their family members and carers accessible information about all the potential care options available for end of life care, including hospice services.

Making sure end of life care is person centred

1.6.2 Practitioners providing end of life care should spend time getting to know the person to understand their needs. Get to know how they communicate, their cultural background, what they like and dislike, how they express pain, their health conditions and the medication they are taking. Be aware that this understanding will make it easier to identify when the person's health is deteriorating.

1.6.3 Identify who the person would like to involve in creating their end of life plan. Include the person themselves and everyone who supports them in discussions and planning.

1.6.4 Ask the person regularly who they would like to involve in discussions about their end of life plan, in case they change their mind. Do this every 6 months or more often if the person is close to the end of life.

1.6.5 Make it possible for the person to die where they wish. This might include adapting their home, working with other practitioners and advocates, and talking to other residents or family members about changes that could be made (for example, moving the person to a room on the ground floor).

Involving families and support networks

1.6.6 During end of life care planning, talk to the person and their family members and carers to understand the person's wishes and any cultural needs at the end of the person's life.

1.6.7 When providing end of life care, learn from family members and carers about the person's needs and wishes, including those associated with faith and culture, nutrition, hydration and pain management. This is particularly important if the person is unable to communicate.

1.6.8 Learning disability providers delivering care at the end of life should work collaboratively and share information with other practitioners and services involved in the person's daily life.

1.6.9 Social care providers should work in partnership with healthcare providers to share knowledge about the person and to develop expertise for end of life care.

1.6.10 Provide training, information and support for family members and carers, for example in medication, pain, nutrition and hydration, to enable the person to die where they wish to.

1.6.11 Make sure that key people in the support network have the knowledge, confidence and understanding to communicate with the person about their illness and death. This includes discussion about symptoms, pain management and preferences about resuscitation.

1.6.12 Mainstream end of life care services should make reasonable adjustments to support the person, their family members, friends and carers and other people they live with throughout palliative and end of life care and bereavement.

1.6.13 For further guidance on end of life care see NICE's guideline on care of dying adults in the last days of life.

1.7 Workforce skills and expertise

1.7.1 Managers in health and social care services should ensure that staff in older people's services have the expertise to support older people with learning disabilities from a wide range of backgrounds.

1.7.2 Managers in health and social care services should ensure that learning disability staff have the skills and understanding to support people's changing needs as they grow older. Provide this skilled support in all settings, including people's own homes.

1.7.3 Managers in health and social care services should ensure that all staff working with older people with learning disabilities have skills and knowledge in:

- communication methods, including non-verbal communication

- building good relationships with people with learning disabilities and making them feel at ease
- the physical and mental health needs of older people with learning disabilities, related to both their age and disability
- common health conditions to which older people with learning disabilities are predisposed, for example the earlier onset of dementia, ensuring that they do not confuse these with the person's learning disability or another condition.

1.7.4 Managers in health and social care services should provide opportunities for learning disability staff and practitioners working with older people to share expertise with each other as part of their knowledge and skills development.

1.7.5 Staff should know what local services are available (including housing options) so they can support older people with learning disabilities, families, carers and advocates to make informed choices about their care and support.

Workforce skills and expertise for supporting end of life care

1.7.6 Commissioners and providers of end of life care should recognise the complex needs of older people with learning disabilities. They should provide ongoing training for staff to ensure they have the expertise to provide good-quality coordinated care, enabling people to die in their own home or another place of their choice. Training should include:

- having discussions about resuscitation intentions
- finding out and responding to cultural preferences
- managing symptoms, pain and medication
- nutrition and hydration
- understanding communication preferences and being able to communicate – this might include using an augmentative communication system.

1.7.7 Provide in-service training for learning disability and palliative care practitioners so they have the skills to support people at the end of life. This might include joint study days and training of professionals by people with learning disabilities and their family members and carers.

Terms used in this guideline

Annual health check

An NHS initiative for adults and young people aged 14 and over with learning disabilities for the reason that they often need more health support and may have health conditions that would otherwise go undetected.

Family members and carers

This includes people related to the person with a learning disability and others who help to provide support for that person, for example friends. It does not cover staff who are paid to provide care or support.

Hospital passport

Hospital passports are designed to give hospital staff useful information that is not limited to illness and health. For example, it could include details about what the person likes and dislikes, in terms of physical contact or food and drink. The idea is to help hospital staff understand how to make the person feel comfortable.

Older people with learning disabilities

For the purpose of this guideline 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 mild, moderate, severe or profound in severity. Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability. A specific age limit is not used to define older people because adults with learning disabilities typically experience age-related difficulties at different ages, and at a younger age than the general population.

Practitioner

In this guideline 'practitioner' is used to mean a health or social care practitioner who provides care and support for older people with learning disabilities.

Support network

All the people who provide emotional and practical help to a person with a learning disability. A person's support network could include their family (including siblings), friends, carers, advocates, non-family members living with the person in supported housing and members of the person's religious community.

For other social care terms see the Think Local, Act Personal Care and Support Jargon Buster.

2 Research recommendations

The Guideline Committee has made the following recommendations for research.

2.1 Models of care and support at home

Research question

What is the effectiveness and cost effectiveness of care and support models (for example, assistive technology) for older people with learning disabilities to enable them to live in the family home?

Why this is important

There is no evidence from studies published later than 2005 about the effectiveness of care and support models for older people with learning disabilities living in the family home, or about their experiences of that support. For example, we did not identify any evidence on the effectiveness of assistive technology for supporting older people with learning disabilities and their ageing family carers. Comparative studies are needed to evaluate the impact of different approaches, like assistive technology, on care and support for older people with learning disabilities in the family home. Resource use information, demonstrating the impact on unpaid care (whether it increases or decreases as a result of the different support models) is also needed as well as outcome data relating to families and carers. These should be supplemented by qualitative studies to explore the views and experiences of older people with learning disabilities, including those from minority backgrounds, and their families and carers in relation to different models of support.

Criterion	**Explanation**
Population	Older people with learning disabilities
Intervention	Different approaches to providing care and support in the family home, e.g. the use of assistive technology
Comparators	Other approaches, e.g., those which do not involve assistive technology
Outcomes	Health and social care-related quality of life health and social care service use delayed transfers of care from hospital hospital admissions and readmissions admission to care homes inappropriate admission to residential care housing support use Service user and carer-related experience: acceptability accessibility satisfaction quality and continuity of care choice and control dignity and independence involvement in decision-making practice of reasonable adjustments in care
Study design	Comparative studies including randomised controlled trials (RCTs) and cost-effectiveness studies of the specific interventions Qualitative data from service users, carers and practitioners
Timeframe	Comparative studies should be of sufficient duration (for example, 1–2 years) to capture relevant outcomes and the economic impact of the intervention

2.2 Identifying health conditions

Research question

What is the effectiveness and cost effectiveness of different ways of identifying age-related and other physical and mental health conditions, in older people with learning disabilities?

What can mainstream and specialist health services do to facilitate:

- early identification of health conditions in older people with learning disabilities?
- equal access to health services in older people with learning disabilities?

Why this is important

Apart from studies on annual health checks, we did not find any evidence about different methods and pathways for identifying health conditions among older people with learning disabilities. There is a need for effectiveness and cost-effectiveness studies using longitudinal, comparative designs to evaluate the costs and outcomes of different approaches to identifying health conditions in older people with learning disabilities. These should be complemented by qualitative studies to explore the views and experiences of older people with learning disabilities, including those from minority backgrounds, and their families, carers and practitioners on the facilitators and barriers of these approaches. This includes their views on how, where and by whom these services should be provided.

Criterion	**Explanation**
Population	Older people with learning disabilities
Intervention	Different approaches to identifying health conditions
Comparators	‘Usual’ or ‘standard’ approach such as annual health checks
Outcomes	Health and social care-related quality of life: health and social care service use delayed transfers of care from hospital hospital admissions and readmissions admission to care homes inappropriate admission to residential care housing support use Service user and carer-related experience: accessibility satisfaction quality and continuity of care choice and control dignity and independence involvement in decision making practice of reasonable adjustments in care
Study design	Longitudinal studies of comparative designs and cost-effectiveness studies of the specific interventions Qualitative data from service users, carers and practitioners

Timeframe	Comparative and longitudinal studies should be of sufficient duration (e.g. 2–3 years) to enable assessment on patient outcomes and the economic impact of intervention

2.3 Education and training programmes: self-management

Research question

What is the effectiveness and cost effectiveness of education programmes to improve information and advice and to support self-management of chronic health conditions (for example obesity, diabetes and cardiovascular disease) for older people with learning disabilities and their family members and carers?

Why this is important

Evidence suggests that older people with learning disabilities value the medical knowledge and authority of health professionals. There is a small amount of evidence that practitioners could play a greater role in providing education and advice to support self-management of health conditions in older people with learning disabilities. There is also evidence that families and carers play a central role in supporting and advising older people with learning disabilities about their health conditions and promoting healthier lifestyle choices.

Comparative effectiveness and cost-effectiveness studies are needed to evaluate the impact of education programmes to support self-management for older people with learning disabilities. These need to be supplemented with studies exploring the views and experiences of older people with learning disabilities, including those from minority backgrounds, and their families, carers and practitioners, on the accessibility and acceptability of different approaches to supporting self-management and communicating health messages.

Criterion	**Explanation**
Population	Older people with learning disabilities
Intervention	Service with provision for training and education for self-management
Comparators	Service with no provision for training and education for self-management
Outcomes	Health and social care-related quality of life Health and social care service use Service user and carer-related experience:

	acceptability accessibility satisfaction quality and continuity of care choice and control dignity and independence involvement in decision-making practice of reasonable adjustments in care
Study design	Comparative studies including RCTs and cost-effectiveness studies of the specific interventions Qualitative data from service users, carers and practitioners
Timeframe	Comparative studies should be of sufficient duration (e.g. 1–2 years) to capture relevant outcomes and the economic impact of intervention

2.4 Dementia education and training programmes for family members and carers

Research question

What is the effectiveness, cost effectiveness and acceptability of training programmes (for example in the use of life story work) for families of older people with learning disabilities who have dementia or are at risk of developing it?

Why this is important

No evidence was found from studies published later than 2005 about the effectiveness and cost effectiveness of interventions or training programmes for family members and carers of older people with learning disabilities. There is some evidence that some family members and carers of older people with learning disabilities and dementia need specialist training in dementia care.

Comparative effectiveness and cost-effectiveness studies are needed to evaluate the impact of specific interventions or training programmes for families and carers of older people with learning disabilities, including for people living with conditions such as dementia. Qualitative studies are needed to explore the views and experiences of family, friends and carers of older people with learning disabilities, including those from minority backgrounds, about these training programmes.

Criterion	**Explanation**

Population	Older people with learning disabilities
Intervention	Service with provision for training and education programmes for family carers, including specialist training in dementia care
Comparators	Service with no provision for training and education programmes for family carers, nor specialist training in dementia care
Outcomes	Health and social care-related quality of life Health and social care service use: delayed transfers of care from hospital hospital admissions and readmissions admission to care homes inappropriate admission to residential care housing support use Service user and carer related experience: acceptability accessibility satisfaction quality and continuity of care choice and control dignity and independence involvement in decision-making practice of reasonable adjustments in care
Study design	Comparative studies including RCTs and cost-effectiveness studies of the specific interventions Qualitative data from service users, carers and practitioners
Timeframe	Comparative studies should be of sufficient duration (e.g. 1- 2 years) to capture relevant outcomes and the economic impact of the intervention.

2.5 Advance planning about end of life care

Research question

What is the effectiveness and cost effectiveness of advance care planning about end of life care for older people with learning disabilities, and their family members and carers?

Why this is important

We identified no studies evaluating advanced care planning for end of life care in older people with learning disabilities, and their family members and carers. Such studies would help to determine how and what reasonable adjustments should be made to ensure that older people with learning disabilities receive appropriate care at the end of life. Longitudinal studies should have a naturalistic design with a control group to follow up families and carers who have used advanced care planning for end of life care in older people with learning disabilities.

Criterion	**Explanation**
Population	Older people with learning disabilities
Intervention	Service with advance care planning about end of life care
Comparators	Service with no advance care planning about end of life care
Outcomes	Health and social care-related quality of life Health and social care service use Service user and carer related experience: acceptability accessibility satisfaction quality and continuity of care choice and control dignity and independence involvement in decision-making practice of reasonable adjustments in care
Study design	Longitudinal studies of a naturalistic design with a control group to evaluate the long-term impact on patient outcomes, costs and the processes of the specific intervention Qualitative data from service users, carers and practitioners
Timeframe	Comparative and longitudinal studies should be of sufficient duration (e.g. 2–3 years) to evaluate long-term patient outcomes and processes of the intervention

2.6 Personalised technology for building social contact

Research question

What is the effectiveness and cost effectiveness of personal technology and social media to help older people with learning disabilities to maintain relationships with friends and family, build social contacts and access volunteering, social and leisure activities?

Why this is important

There is some evidence that older people with learning disabilities who live in residential settings are less well connected with friends and their local community than people living in their family home. This poses barriers to building social contacts, accessing volunteering, social and leisure activities and maintaining relationships with friends and family.

Comparative studies are needed to evaluate the effectiveness and cost-effectiveness of personalised technology and social media in building social contacts, accessing volunteering and maintaining relationships with family, friends and the local community for older people with learning disabilities. Qualitative studies are needed to explore the views and experiences of older people with learning disabilities, including those from minority backgrounds, their carers and practitioners on the use of personalised technology and social media in building social contacts to improve quality of life for older people with learning disabilities.

Criterion	**Explanation**
Population	Older people with learning disabilities
Intervention	Building social contacts and accessing meaningful leisure activities by means of personalised technology such as social media
Comparators	Other means of building social contacts and accessing meaningful leisure activities without personalised technology such as social media
Outcomes	Health and social care-related quality of life Health and social care service use Service user and carer-related experience: accessibility satisfaction choice and control dignity and independence involvement in decision-making practice of reasonable adjustments in care
Study design	Comparative studies including RCTs and cost-effectiveness studies of the specific interventions Qualitative data from service users, carers and practitioners
Timeframe	Outcomes need to be measured over 1 or 2 years to enable assessment on relevant patient outcomes and the economic impact of intervention

2.7 Telemonitoring for understanding and managing health

Research question

What is the effectiveness and cost effectiveness of telemonitoring for older people with learning disabilities in:

- promoting understanding and improving management of chronic physical and mental health conditions?
- supporting their ageing family carers to continue providing care?

What are the mechanisms that make telemonitoring accessible and acceptable to older people with learning disabilities?

Why this is important

There is limited evidence that telemonitoring informs and improves the understanding that older people with learning disabilities have about their health conditions. It may also contribute to the support provided by their ageing family carers. Comparative studies are needed to assess the effectiveness and cost-effectiveness of different types of tele-monitoring in promoting understanding of their conditions and improving outcomes for older adults with learning disabilities. Qualitative studies are needed to explore the views and experiences of older people with learning disabilities, including those from minority backgrounds, their families and practitioners on how tele-monitoring works for people, their carers and social workers.

Criterion	**Explanation**
Population	Older people with learning disabilities
Intervention	Service with telemonitoring for understanding and managing health conditions
Comparators	Service with no telemonitoring for understanding and managing health conditions
Outcomes	Health and social care-related quality of life Health and social care service use Service user and carer related experience: acceptability accessibility satisfaction

	quality and continuity of care choice and control dignity and independence involvement in decision-making practice of reasonable adjustments in care
Study design	Studies of comparative design including RCTs and cost-effectiveness studies of the specific interventions Qualitative data from service users, carers and practitioners on how telemonitoring works for them
Timeframe	Outcomes and service use need to be measured over 1 or 2 years to enable assessment on relevant patient outcomes and the economic impact of intervention

2.8 Care and support at the end of life

Research question

What is the effectiveness and cost effectiveness of end of life care for older people with learning disabilities?

What can mainstream health and social care services do to support older people with learning disabilities and their primary carer (both family and paid carers) at the end of life?

Why this is important

No evidence was found from studies published later than 2005 about the effectiveness or cost effectiveness of end of life care for older people with learning disabilities. Comparative studies are needed to evaluate the effectiveness and cost-effectiveness of end of life care for older people with learning disabilities. Qualitative studies are needed to explore the views and experiences of older people with learning disabilities, including those from minority backgrounds, their families, carers and practitioners on how mainstream and palliative care services support older people with learning disabilities at the end of life.

Criterion	**Explanation**
Population	Older people with learning disabilities
Intervention	Service with end of life care provision
Comparators	Service with no end of life care provision
Outcomes	Health and social care-related quality of life

	Health and social care service use Service user and carer related experience: accessibility satisfaction choice and control dignity and independence involvement in decision-making practice of reasonable adjustment in care
Study design	Comparative studies including RCTs and cost-effectiveness studies of the specific interventions Qualitative data from service users, carers and practitioners, the latter in their views on how best mainstream services can support older people with learning disabilities at the end of life
Timeframe	Outcomes and service use need to be measured over 1 or 2 years to enable assessment on patient outcomes and the economic impact of intervention

3 Evidence review and recommendations

We used the methods and processes in Developing NICE guidelines: the manual (2014). For more information on how this guideline was developed, including where non-standard methods were used or there were deviations from the manual as agreed with NICE, see Appendix A.

The target group for this guideline was defined as older people with learning disabilities who have care and support needs, irrespective of whether they are known to health and social care services. A specific age limit was not used to define older people because adults with learning disabilities typically experience age-related difficulties at different ages, and at a younger age than the general population. Without a specific age cut-off, the systematic reviewers endeavoured to discern whether seemingly relevant papers referred to issues, services or experiences associated with growing older with a learning disability. Any doubts were clarified through full text screening and in discussion with the Guideline Committee.

In terms of defining learning disability, scoping and consultation established that the definition used in ‘Valuing people’ (Department of Health 2001) would be used in this guideline. In ‘Valuing people’, a learning disability is defined as ‘a significantly reduced ability to understand complex information or learn new skills (impaired intelligence); a reduced ability to cope independently (impaired social functioning); a condition which started before adulthood (18 years of age) and has a lasting effect'. The term 'learning disability' in this guideline implies pervasive or global learning disabilities affecting most aspects of social functioning, and not specific learning disabilities (for example, dyslexia).

Again, any difficulties in identifying the population during the review process were overcome through close working with the Guideline Committee and examination of the descriptions in the full text of the study.

How the literature was searched

A total of 9 review questions underpinned the review. Two questions (1 and 9) focused only on the views and experiences of older people with learning disabilities, whereas question 2 focused only on the views and experiences of practitioners. Six review questions (numbers 3, 4, 5, 6, 7 and 8) included sub-questions (Part a) which examined the acceptability, effectiveness and cost-effectiveness of interventions designed to improve certain aspects of the delivery of care and support to this population. Part b of these review questions sought to identify evidence that described the self-reported views and experiences of adults with learning disabilities about certain aspects of care and support, and of their families and unpaid carers. Finally, part c of these review questions sought evidence that described the views and experiences of people delivering, organising and commissioning social care, and health and housing services, including evidence on what does and does not work well in providing certain aspects of care and support for people with learning disabilities.

A single search was created for question numbers 1–7 and 9 and a unique search was created to find research literature relating to question 8 (end of life care for older people with learning disabilities). For both, electronic databases in the research fields of health (including mental health), social care, social science and economics were searched using a range of controlled indexing and free-text search terms. Additional searches of websites of relevant organisations, and trials registries, were undertaken to capture literature that may have been missed from the database searches. The searches intended to find studies on effectiveness and cost-effectiveness, and on views and experiences of older people with learning disabilities and their carers and health, social care and other practitioners.

The single search was based upon 2 concepts: a) older people, ageing and future planning, or aged care services; and b) intellectual or learning disabilities. The unique search on question 8 was based upon: a) people with learning disabilities; and b) end of life care, terminal illness and advance care planning.

A wide range of search terms were used to find these 2 concepts. The search terms were developed from various methods, including discovering search terms from other evidence reviews, test searches and from research previously published on the topic.

Searches for the single search were undertaken in January 2016 for the databases, with website searches for the single search undertaken in April 2016. Update searches were undertaken in February 2017 on the databases for the single search.

Searches for the unique search were undertaken in February 2017 for the databases and April 2017 for the websites. No update searches were undertaken for the unique search due to the timing of the original search.

See Appendix A for full details of the search, including update search.

How studies were selected

The results of the searches were screened on title and abstract and then full text using criteria based on the guideline scope and protocol. The included studies were critically appraised using tools highlighted in the manual and the results tabulated (see Appendix B for tables). Minor amendments were made to some of the checklists to reflect the range of evidence and types of study design considered in the evidence reviews. For more information on how this guideline was developed, including search strategies and review protocols, see Appendix A.

We presented the ‘best available’ evidence identified. Studies were rated for internal validity (how convincing the findings of the study are in relation to its methodology and conduct) and external validity (how well the study relates to the review question, particularly its applicability, in terms of setting and population) using ++/+/- (meaning good, moderate and low). The internal quality rating is given in the evidence statements with both the internal and external rating reported in the narrative summaries and in the evidence tables in Appendix B.

The critical appraisal of each study takes into account methodological factors to assess internal validity such as:

- whether the method used is suitable to the aims of the study
- whether random allocation (if used), including blinding, was carried out competently
- sample size and method of recruitment
- loss to follow-up
- transparency of reporting and limitations that are acknowledged by the research team.

Critical appraisal also assesses the external validity of each study, judging the extent to which samples are relevant to the population we are interested in and whether the research question matches the guideline review questions.

Evidence rated as of only moderate or low quality was included in evidence statements, and taken into account in recommendations, where the Guideline Committee independently and by consensus supported its conclusions and thought a recommendation was needed.

A further table reports the details (such as aims, samples) and findings. For full critical appraisal and findings tables, arranged alphabetically by author(s), see Appendix B.

3.1 Identifying, assessing and reviewing health, social care and housing needs

Introduction to the review questions

Review questions 1 and 2 are described together in this sub-section, due to the overlap in their focus. The purpose of the first review question was to examine the views and experiences of older people with learning disabilities about the way that their health, social care and housing needs are identified and reviewed. The question also sought data on the views of families and carers. In particular, question 1 aimed to understand whether older people with learning disabilities, their families and supporters think that care and support needs are identified, assessed and reviewed in a way that is personalised and coordinated across social care, health and housing services. The focus was also on whether needs are identified in a way that is age appropriate and accounts for future changing circumstances such as families or carers no longer being able to provide support.

The second review question sought to locate data about practitioners' views on the way that health, social care and housing needs are identified and reviewed for older people with learning disabilities. In particular, the question was used to try and identify emerging models and approaches to identification, assessment and review of the needs of older people with learning disabilities. Also, to describe what practitioners' experiences are of identification, assessment and review of care and support needs including what works and what does not work well.

Review questions

1. What are the views and experiences of older people with learning disabilities and their carers about how health, social care and housing needs are identified, assessed and reviewed?
2. What are the views and experiences of health, social care and other practitioners about how the health and social care needs of older people with learning disabilities and their carers are identified, assessed and reviewed?

Summary of the review protocol

The protocol sought to identify studies that would:

- Describe the self-reported views and experiences of older people with learning disabilities, their families, carers and supporters; also of people delivering, organising and commissioning social care, health and housing services about the identification, assessment and review of care and support needs, including what does and does not work well.
- Consider specifically whether older people with learning disabilities, their families, supporters and health, social care and housing practitioners think that care and support needs are identified, assessed and reviewed in a way that is holistic,

personalised and coordinated across social care, health, housing, employment and education services.

- Consider specifically whether older people with learning disabilities their families, supporters and health, social care and housing practitioners think that their care and support needs are identified, assessed and reviewed in a way that is age appropriate and accounts for future changing circumstances such as families or carers no longer being able to provide support.

Population

Older people with learning disabilities, their families and carers.

Social care practitioners (providers, workers, managers, social workers), housing practitioners and health and social care commissioners involved in delivering care and support at home to older people with learning disabilities.

Intervention

Identification, assessment and review of the care and support needs of older people with learning disabilities and assessment of their carers' needs and their own needs as carers. Includes assessment and review of health, social care and housing related needs by all relevant practitioners.

Setting

People's own homes, family homes and temporary accommodation such as hostels and respite arrangements; supported living, residential and nursing care homes (including hospices). Primary healthcare, outpatients and community hospitals.

Outcomes

Person-focused outcomes (independence, choice and control over daily life; ability to achieve desired person-centred outcomes; user and carer satisfaction; continuity of care; health and social care-related quality of life, including carer quality of life; years of life saved) and service outcomes (use of health and social care services and housing support; need for support from health and social care practitioners and carers; delayed transfers of care from hospital; hospital admissions and readmissions; admission to care homes; length of stay in hospital and care homes). See 1.6 in the scope.

Study design

The study designs relevant to this question included: systematic reviews of qualitative studies on this topic; qualitative studies of user and carer views of social and integrated care; qualitative components of effectiveness and mixed methods studies; observational and cross-sectional survey studies of experiences of users, carers and health, social care and other practitioners.

See Appendix A for full protocols.

How the literature was searched

A single search was conducted for all but 1 of the review questions (end of life care). Electronic databases in the research fields of health (including mental health), social care, social science and economics were searched using a range of controlled indexing and free-text search terms. Additional searches of websites of relevant organisations, and trials registries, were undertaken to capture literature that may have been missed from the database searches. The search was based upon 2 concepts: a) older people, ageing and future planning, or aged care services; and b) intellectual or learning disabilities.

A wide range of search terms were used to find these 2 concepts. The search terms were developed from various sources. This included finding 52 items that related to the topic, and discovering relevant search terms.

See Appendix A for full details of the search.

How studies were selected

Search outputs (title and abstract only) were stored in EPPI Reviewer 4 – a software program developed for systematic review of large search outputs. Coding tools were applied and all papers were screened on title and abstract. Formal exclusion criteria were developed and applied to each item in the search output, as follows:

- Language (must be in English).
- Population (for question 1, must be about older people with learning disabilities, their families and supporters. Note that in line with the scope, a specific age limit will not be used to define older people so a flexible and pragmatic approach to screening on the target population will be taken. For question 2, must be about

social care practitioners involved in delivering care and support at home to older people with learning disabilities).

- Intervention (must be about views and experiences of adults, their families, carers, supporters and social care practitioners about the identification, assessment and review of care and support needs, including what works and what does not work well).
- Setting (must be people's own homes, family homes and temporary accommodation such as hostels and respite arrangements; supported living, residential and nursing care homes, including hospices. Primary healthcare, outpatients and community hospitals).
- Country (must be UK or other OECD).
- Date (must not be published before 2005).
- Type of evidence (must be research).

Title and abstract of all research outputs were screened against these exclusion criteria. Those included at this stage were marked for relevance to specific review questions and retrieved as full texts.

Full texts were again reviewed for relevance and research design against NICE recommended tools. A list of studies excluded on full text can be found in Appendix A, organised by exclusion criteria.

If still included, critical appraisal (against NICE tools) and data extraction (against a coding set developed to reflect the review questions) was carried out. The coding was all conducted within EPPI Reviewer 4, and formed the basis of the analysis and evidence tables. All processes were quality assured by double coding of queries, and of a random sample of 10%.

See Appendix B for full critical appraisal and findings tables.

Overview of evidence

In our initial screen (on title and abstract) we found 88 studies which appeared relevant to review questions 1 and 2. We retrieved and then reviewed full texts and included a total of 12 papers. For question 1, there were 7 studies, which on average were moderate in terms of their internal validity. Only 1 study of moderate quality specifically answered question 2 and a further 4 studies provided data to answer both questions 1 and 2 because they reported practitioner views as well as views of older people with learning disabilities and their carers or families. There were gaps in the evidence about assessment and review of needs, with most of the data covering future planning. The gaps in the data led to discussions based on Committee expertise, with crucial input from the experts by experience.

Narrative summary of the evidence

In this section, a narrative summary of each included study is provided, followed by a synthesis of the evidence, according to the key outcomes, themes or sub-groups in the form of evidence statements (p46). The approach to synthesising evidence was informed by the PICO within the review protocol.

Please note that the following studies provide data to help answer both questions 1 and 2, due to the overlap in the focus of the review questions.

1. Bigby C, Bowers B, Webber R (2011) Planning and decision making about the future care of older group home residents and transition to residential aged care. Journal of intellectual disability research 55: 77–89

Methods: Qualitative

Data: Views and experiences

Country: Australia

Outline

This study, conducted in Australia, was judged as good quality (++) and is relevant to the review question (++), particularly the issue of future planning. The study aimed to explore the perceptions of families, group home staff and managers about the future of older residents with intellectual disability and the decision that a move to residential care was necessary. The researchers used a method called ‘grounded dimensional analysis’ to guide data collection and analysis. (This means that the data collected leads to the development of a theory instead of an existing theory being used to shape the collection and interpretation of data.) Three sets of interviews were carried out over an 18-month period. For each of 17 older group home residents 1 of their family members was interviewed as well as their house supervisor and programme manager. Questions centred on the process of decision-making about the possible move to residential care.

Findings

The perspectives of family members

Many families had hoped that their relative would be cared for in the group home for their whole lives. Some had invested in their care in the hope that the group home would provide long-term care. Two families expressed their disappointment when they found that staff could not accommodate escalating needs.

In thinking about the future, some families had clearly not considered the possibility that their relative would need to move to an old people’s home or a care facility: ‘they said we’ll keep them all their life and there was an old people’s home around and I thought well that’s what they’ll do, they’ll all go on to the next stage’ (p782). For some, the interview process itself prompted families to consider future plans for the first time: ‘I haven’t thought about it. There’s been no plan, no thinking, and no discussion at all … And somehow in my mind I thought there was some magic place within Bethel they moved them on, but I’m realising that there isn’t and he will become part of the aged care federal government system which is absolutely terrifying’ (p782).

On the other hand, some families had thought about what the future would hold: ‘I fully expect that one day he will be in a nursing home because the staff won’t be able to manage five elderly men who will all have some form of dementia’ (p782).

The perspectives of practitioners

In terms of future planning and meeting needs, staff acknowledged that residents would need to move on once their needs ‘crossed a line’. Views varied about how health needs would escalate to reach this point. Generally, staff said that residents would move on when it was felt their needs would be better met elsewhere. Some said the point would come when the person’s condition changed and the staff were not equipped to provide care: ‘the person has actually been assessed as needing nursing home care, we can’t provide that care …’ (p782).

The findings seemed to suggest that the decision about a person’s needs reaching the point at which they would have to move out was subjective and highly variable. It depended on the home and the staff group, with the staff drawing a line when they felt they could no longer fulfil a ‘duty of care’ (p783). Some cited escalations in people’s medical or personal care needs, factors like ‘medical procedures, mobility issues and personal care tasks’ (p783). If it ‘becomes really a proper nursing thing that they need injections or they need really complex dressing and things like that, wound care and things like that because we just don’t have that care. But if it’s short-term that’s not a problem, we’re talking about long term’ (p783).

Deciding to move to an aged care environment (families and practitioner views)

During the 18-month study, 17 residents made the decision to move. Six moved and the rest did not because there was a delay or the decision was overturned. Staff described how each decision is different but the common thread was the question about the significance of changes in care and support needs, impact of changes on staff and other residents, and how flexible the home could be to these needs.

An acute episode or stressful situations happening in the house were often a trigger for the move, although some were made over time with family input: ‘So he, [HM] told me to more or less start to look for alternative accommodation because they couldn’t manage in the house, you know?’ (p784).

Other decisions were reached without warning and with little consultation with the family. These sudden moves left people feeling bewildered and some resisted the proposed move. ‘After a while I got cross, and I rang them and I said: “I think you are trying to push him out. Well, I don’t like any of the places that the broker has sent us to, and other places, and I don’t, and he’s lived there for 35 years …” This is, it’s his home, you know, it’s like his family too up there’ (p785).

2. Bigby C, Webber R, Bowers B (2015) Sibling roles in the lives of older group home residents with intellectual disability: working with staff to safeguard wellbeing. Australian Social Work 68: 453–68

Methods: Qualitative

Data: Views and experiences

Country: Australia

Outline

This is a qualitative study, which was moderately well conducted (+). The researchers interviewed the staff and carers surrounding 13 older people with learning difficulties in Australian group homes. The study aimed to look at the role of siblings in the care of older people with learning difficulties and the relationships between siblings and staff. A total of 14 siblings, 13 supervisors and 4 managers participated in the semi-structured (face to face) interviews. They were followed up by phone every 6 months for a 3-year period.

Findings

The findings in this paper that relate to review questions 1 and 2 include themes around monitoring needs and coordinating formal care.

Siblings reported having a variety of levels of involvement, from ‘keeping an eye on things’ (p458) to monitoring the care provision: ‘I want to pre-empt anything that might go wrong’ (2F1) (p458).

Siblings commented that their involvement was often informal. Some said that they were only informed when a major change or decision was going to be made. Others were invited to help coordinate care: ‘they [staff] did initiate finding the specialist, talking to people … so they did show the initiative there, but then they brought the information to me and we discussed it and agreed on who would be the best person, and that we would go together and talk to the person’ (13F3) (p458).

Siblings described themselves working in an advocacy role for their brother or sister or providing emotional support relating to their care, by going to medical appointments and discussing implications. ‘A sister explained that she debriefed with her sibling after medical appointments, saying “I always take her [sister] for something, sort of a treat and definitely a cuppa … and give her a chance to bring up anything that might be worrying her”’ (2F1) (p459).

Communication with group home staff is a theme of the analysis. Siblings described how they appreciated an ‘easy partnership’ (p460) with staff. Siblings talked about being in a team with staff, with 1 saying ‘I feel that we are a good team’ (13F2), and another that it has been ‘very comfortable, the communication’s good … the staff and I are involved from the word go’ (2F3) (p460). Siblings described how to maintain good communication with staff through announcing their visits, or sometimes not voicing every concern for fear of alienating the professionals.

Group home staff also commented on the importance of involving siblings and gaining their respect. ‘Managerial staff adopted proactive strategies to bring siblings around to their point of view ... one manager described this approach, saying “we start to have the conversation [with the sibling] to assist and facilitate the conversation to get to the point where it needs to be”’ (3, 4, 5, 6, 10AM1)’ (p461).

Disputes between staff and siblings around care were largely resolved through good communication but there is a discussion of disputes around care not being resolved. For example: ‘I was never actually informed about this [decision for brother to go on holiday] until it was too late … and so I hadn’t been consulted or advised of anything, just came like a bolt out of the blue’ (8F2) (p461).

3. Bowers B, Webber R, Bigby C (2014) Health issues of older people with intellectual disability in group homes. Journal of Intellectual and Developmental Disability 39: 261–9

Methods: Qualitative

Data: Views and experiences

Country: Australia

Outline

This is a moderate quality Australian study (+) in which 30 staff members and residents from a group home were interviewed and then followed up 6 months later. The study aimed to find out how health issues were monitored by staff over time and as residents developed age-related health conditions.

Findings

Monitoring health needs

Staff stated that all residents kept appointments with GPs for general health checks. These appointments led to diagnosis of a variety of conditions, like diabetes, high blood pressure, cholesterol issues and others. Staff spoke highly of the work of GPs with residents: ‘Oh, they have their own doctor who they’ve been going to see for, oh, five years, four years, something like that. And she's an excellent, excellent with them' (#37) (p264).

Staff worked with GPs to make appointments accommodate the needs of service users. This included elongating appointment times, establishing consistency in providers, having appointments at home and taking care not to mention anything that might be alarming. Some staff described bad experiences with GPs: '… she's got Barrett's disease … And they took her to the local GP, to get a referral for the follow-up, and he said: "Well, yes it doesn't really matter that the follow-up hasn't happened, because, after all, she's not normal" … And then they changed doctors, after that' (#94F) (p264).

Tests and screening

Staff were not medically trained so they relied on the expertise of GPs and others to make diagnoses and follow up issues. Some staff were not sure whose responsibility it was to follow up tests: 'Yeah but ultimately, whose responsibility is all that. Do I have to push it? Should someone else?' (#9) (p264). There was variation among staff about responding to screen requests for issues like breast cancer or cervical cancer. 'We had a gentleman with Down syndrome and he was terrified of doctors and we couldn't get an injection and we couldn't do a blood test. We couldn't do anything. So what we did instead of taking him to the doctor we brought the doctor here' (14) (p264).

Some respondents said that residents would not tolerate such tests, while others had developed strategies to encourage residents to have the tests (such as prostate examinations). Some staff did not think that such tests were appropriate: 'We get a lot of feedback from doctors, especially about female's pap smears. "Well they're not sexually active so they don't need a pap smear"' (#63)' (p264).

Some group home staff commented that there were delays in seeking care. Delays were caused by:

- Symptoms being attributed to ageing: 'he's wanted to sleep a lot longer. I think it's just age and you know walking it takes a lot of energy and I think it's just ageing more than anything else' (#22) (p265).

- Residents were perceived as ‘difficult’. ‘He’s up at the toilet … I believe that it’s a boredom thing, not so much boredom because he does a lot of things’ (#70) (p265).
- Issues attributed to dementia. In the case of challenging or unusual behaviour staff sometimes assumed that disruptive behaviour was the onset of dementia. One resident was described as getting up in the night often and disturbing other residents. The problem was later found to be a serious prostate issue. The knowledge that dementia is prevalent among people with learning difficulties led to staff assuming dementia rather than seeking medical advice.
- Communication. Staff felt that the difficulty in identifying health issues was often down to the older person’s communication difficulties: ‘communicate: I don’t know, Trevor wouldn’t really tell you even if something was sore or stiff anyway’ (p266).
- Training. Staff often had no formal training for their roles, and not usually any medical experience. A manager commented that staff would benefit from more training: ‘I’d love to have more training in dementia for them [staff] as well because people are very quick to put labels on other people, you know, you’ve really got to know a little bit more about what is dementia’ (p266).
- Relation to other conditions. Another reason for delays was that symptoms were attributed to existing conditions, and other possibilities were not explored.
- Independence and privacy. Some residents were independent in their personal care and this meant that staff were not aware of problems that may not be clear when they were clothed. Staff were concerned about preserving privacy and did not see problems.

4. Carling-Jenkins R, Torr J, Iacono T et al. (2012) Experiences of supporting people with Down syndrome and Alzheimer’s disease in aged care and family environments. Journal of intellectual and developmental disability 37: 54–60

Methods: Qualitative

Data: Views and experiences

Country: Australia

Outline

The quality of the study's methodology was judged to be moderate (+) and the reviewers judged that the relevance to the review questions was also moderate (+). This was a small-scale study, which investigated the experiences of families and practitioners in supporting people living with Down's syndrome and Alzheimer's disease. The researchers did this by creating case studies based on 3 adults and using a variety of data sources to gather information about those people. Data were analysed thematically.

Findings

Diagnostic overshadowing was an overriding finding. Services and families attributed behaviour changes in the adult with a learning disability to Down's syndrome rather than considering it might be due to the onset of Alzheimer's disease. This resulted in the inability of services to meet people's care and support needs. Families were clearly also unprepared and did not know that their relative with Down's syndrome had an increased risk of developing Alzheimer's disease. They also denied or disbelieved dementia diagnoses. Overall the study found gaps in services, failure to identify need and enormous stress among families.

5. Bowey L, McGlaughlin A (2005) Adults with a learning disability living with elderly carers talk about planning for the future: aspirations and concerns. The British Journal of Social Work 35: 1377–92

Methods: Qualitative

Data: Views and experiences

Country: England, UK

Outline

This UK views study was judged to be of moderate methodological quality (+) and moderate relevance to the review question (+). It presents the experiences, aspirations and concerns of adults with a learning disability about living at home and planning for the future. Forty-one adults with learning disabilities, who all lived at home and had family carers over the age of 70, took part in the study. Participants were interviewed using a service users questionnaire which was developed, with input from advocacy professionals, speech and language therapists, and community learning disability team professionals, to gain this group's views about living at home with their older carers and about future planning. Interviews took place individually and usually in a day centre or other service away from the family home in order to ensure that participants were able to speak freely and without direct influence from their family members.

Findings

Thirty-four of the 41 participants (83%) reported that they helped out at home in some way, highlighting that people with learning disabilities are commonly involved in mutually supportive relationships with ageing family carers. The distinction between 'carer' and 'cared for' is not always clear-cut and this can cause increased anxiety when thinking about alternative housing options.

Thirty (73%) of the participants were aware that their carers would not be able to look after them forever and that they would need to consider alternative forms of housing and support. However, out of those who had discussed future housing, few had made concrete plans, and a third of the participants had not talked about plans for the future at all.

The majority of participants wanted to stay in the family home for as long as possible and were anxious at the prospect of family carers' declining health, and ultimately, their death. This concern often had a negative impact on the whole family's willingness to make plans for the future. The concept of a future where parents were no longer able to care due to death or illness was emotionally troubling, especially as the people with learning disabilities had generally lived their whole lives at home and had not known anything different.

Despite the emotional difficulty involved in considering a time when their parents would no longer be around, the 30 participants who acknowledged the need for future planning were able to express clear preferences for their future housing (shared housing, self-contained accommodation within a shared building, and living with another relative being the most popular choices). Participants spoke of the availability of appropriate support and remaining in their local area as high priorities when considering future housing.

Although in the minority, those who had had the chance to discuss and make future housing plans alongside professionals and their carers felt reassured and were excited at the prospect of increased independence. As opposed to making decisions in a crisis situation, participants who were involved in proactive planning experienced control over decisions about their care and felt empowered. However, some still had concerns about what would happen to their family carers if and when they moved.

6. Coyle CE, Kramer J, Mutchler JE (2014) Aging together: sibling carers of adults with intellectual and developmental disabilities. Journal of Policy and Practice in Intellectual Disabilities 11: 302–12

Methods: Qualitative

Data: Views and experiences

Country: USA

Outline

This US study was conducted moderately well (+). The research involved in-depth, semi-structured interviews with 15 sibling carers of older people with learning difficulties. The average age of carers was 57 and they were mainly female (93%). The average age of the older people with learning difficulties was 55. The aim was to find out about the experiences of sibling carers who were taking a central role in caring for their brother or sister. Interview data was thematically analysed using review software. There were no follow-up interviews.

Findings

Three key themes were identified from the interviews.

1. The impact of ageing on the caring role

Dementia and Alzheimer’s was a common issue in older people with learning difficulties. Sibling carers found it difficult to achieve a diagnosis of dementia or Alzheimer’s. ‘I was asking her about what she did yesterday afternoon and she didn’t remember at al l… day to day you sort of notice certain things’ (p305).

Carers found that as the symptoms of dementia worsened, they had to care more and more for their sibling. Older people with learning difficulties became less mobile, exhibited unpredictable behaviour and lost communication ability. ‘That’s why I left my job. My school day was interrupted with phone calls about medical issues. I was going … every two weeks probably and … would … stay for three, or four or five days. We were then faced with all of the kinds of challenges that families face with AD. [Alzheimer’s] became the primary, pressing issue’ (p306).

2. The importance of planning on the sibling carer role

Sibling carers had to plan for their sibling’s future care and changing condition. ‘I’m sure he’ll live for a long time … [I’m] worrying about making sure that I’m alive too. I’m beginning to think about what we should plan for him, you know, in 10–15 years down the line – where he should live. Should I work on a retirement home?’ (p307).

Taking over caring activities from parents could be sudden and unplanned. Siblings said that they needed to plan for a situation where they may not be around either. This was felt to be a key component of the sibling carer role.

3. Support systems

Siblings struggled to gain adequate support. Other siblings took some role in caring, but the level of their involvement varied. Help within the family tended to decrease over time: ‘I have one sibling who [provides direct care] every Sunday … and gives Jane her lunch … bathes, dresses her and hangs around with her … but that’s planned and scheduled. [The support I provide] is like if Jane is up in the middle of the night, I am up in the middle of night and I have trouble going to the work the next day. It affects my life tremendously as far as work is concerned’ (p309).

Sibling carers found that it was difficult to secure care from formal providers. Sibling carers are well placed to notice changes in their sibling’s condition, but there was a lack of formal support: ‘The group home that he went to was not prepared for [someone with] Alzheimer’s disease … The transition wasn’t smooth …Things that we agreed would happen just didn’t happen’ (p309).

Sibling carers needed support for disability and aging and often services that they had used for some time were no longer relevant. This led to stressful transitions to new services. Siblings found it challenging to coordinate care.

7. Dillenburger K, McKerr L (2011) ‘How long are we able to go on?’ Issues faced by older family caregivers of adults with disabilities. British Journal of Learning Disabilities 39: 29–38

Methods: Qualitative

Data: Views and experiences

Country: Northern Ireland, UK

Outline

This is a moderate quality (+) qualitative study that uses semi-structured interviews to explore the issues related to caring and future planning in Northern Ireland. The study aimed to give older caregivers (n=29; age range 47 to 84; average age 65.17 years) a voice, and interviews used open-ended questions to enable participants to introduce new topics, tell their story in their own words and add their own interpretation of experiences and views. Seventeen participants took part in interviews by themselves and 12 took part in interviews as a couple. There was a broad range of disabilities in the 27 dependants: all of them were affected by learning/developmental disabilities but others also had comorbid mental health problems such as depression, or had limitations in relation to their speech or mobility. Findings were analysed using interpretative phenomenological analysis (IPA) and analysis was undertaken by 2 researchers.

Findings

Future planning

The vast majority had not made long-term plans for the future care of their sons or daughters (n=21; 72%). Others were clear about what would happen because they had made plans – for example, that their daughter would take the house and look after their son with disabilities.

Almost a quarter of family carers (n=7) were worried about their own health and wellbeing, and future planning (10%; n=3). ‘Our biggest problem, as far as [our children] are concerned, is how long are we able to go on? We think a lot about that ... and we haven’t come up with an answer’ (p34).

Some parents even expressed that their son/daughter's own death was preferable to being taken into care. 'I really don't want him in a home, so I just hope that God will take him before he takes us, but that's not always the way, so you have to think of these things' (p39).

Participants spoke of the anxiety that thinking about what will happen if they die causes their son or daughter. This panic that their children had voiced themselves prevented parents from discussing future planning with them.

The majority of participants (66%; n=19) had not discussed future provision with social services. 'I don't see them or know anything about them. I know they are there but someone said it's pretty hard to get your social worker, so I haven't bothered' (p39).

Most participants (72%; n=21) had not considered making financial arrangements for the future, despite knowing that they 'should be thinking about it' (p39). The importance of future planning was understood by the majority of participants but there was still reluctance to have to 'face up to it' and as a result many participants never acted on it.

8. Hole RD, Stainton T, Wilson L (2013) Ageing adults with intellectual disabilities: self-advocates' and family members' perspectives about the future. Australian Social Work 66: 571–89

Methods: Qualitative

Data: Views and experiences

Country: Canada

Outline

This paper presents the qualitative findings of research conducted in British Columbia (BC), Canada. The research explored the future perspectives of 11 ageing adults with intellectual disabilities and 11 family members. The study was methodologically strong (++) although, partly because it was set in Canada, it was only moderately relevant to the review question (+).

In the study, the researchers aimed to recruit people who met the following criteria: (a) they were an individual who receives, or who is eligible to receive, services from the Crown Agency responsible for community living supports and services in BC or a family member of an individual with intellectual disabilities who is in receipt of, or eligible to receive, services from the Crown Agency; and (b) they were an individual with intellectual disability, age 50+ or an individual with a family member with intellectual disabilities age 50+.

Findings

Future concerns of the adults with intellectual disabilities included concerns for their ageing parents, for their future living arrangements and about loneliness. Family members concerns centred on ensuring the future security of their loved one with an intellectual disability, addressing legal issues and financial security, and promoting future choice and self-determination. The results point to the importance of early and intentional planning that supports and balances the needs and desires of both ageing adults with intellectual disabilities and family members.

9. Innes A, McCabe L, Watchman K (2012) Caring for older people with an intellectual disability: a systematic review. Maturitas 72: 286–95

Methods: Qualitative systematic review

Data: Views and experiences

Country: Various

Outline

This paper reports a systematic review, which was judged to be low quality (-). The systematic review critically evaluates the research on ageing among people living with a learning disability. The searches were conducted among international literature published in the English language. Forty-two papers were included and they were organised under 3 categories: studies from the perspective of older people with an intellectual disability (13), studies about carers of older people with an intellectual disability (14) and, finally, studies about service provision (15).

Findings

Findings from studies about the views of people using services relate to concerns about accommodation, experiences of services and perceptions of ageing, with a common underlying finding being unmet need.

From the studies about carers, it was clear that families and supporters feared the future but were often unwilling or unable to undertake forward planning. Others hadn't got round to it, especially those who were coping well. Another reason for not having done any future planning was a lack of confidence about the available housing options (perhaps because of a bad experience in the past). It was clear that older carers need proactive support with future planning. Carers (and practitioners) had worries about the risks associated with independent living.

From the studies about service provision, the main theme was difficulty in identifying needs. In settings designed for people with intellectual disabilities, changes experienced because of ageing were attributed to 'old age' but in generic ageing services (for example, older people's homes), they were thought to be due to the person's intellectual disability. The authors observe that this means the person may not receive appropriate care and treatment.

10. Towers C (2013) Thinking ahead: improving support for people with learning disabilities and their families to plan for the future. London: Foundation for People with Learning Disabilities

Methods: Mixed, quantitative and qualitative

Data: Views and experiences

Country: UK

Outline

This is a report from a survey and workshops, which took place as part of the 'Thinking Ahead' project. The quality of the study was judged as low (-). At the start of the project, workshops were held with people with mild or moderate learning disabilities who belonged to an advocacy group. They were asked their opinion on their own future planning. Workshops were also held with family carers to gain an insight into their views on and experiences of planning for the future. A survey involving over 300 parents with a son or daughter with learning disabilities aged 18 or over was conducted to explore families' personal experiences and what they would find most helpful for future planning.

Findings

Parents have extremely high levels of anxiety and fear about the future. Over 80% were extremely worried or worried about whether their son or daughter would have a place to live where they were happy once they were unable to care for them. A similarly high percentage (86%) were worried about whether or not their son or daughter would get the support they need. Families reported a lack of clear or accurate information on housing and support options, and only a minority had spoken to a professional about future, person-centred and emergency planning.

People with learning disabilities said that there were too many restrictions placed on their lives and that being mollycoddled did not promote confidence or coping skills, which would be necessary once their parents were no longer around. The focus tended to be on their disability, rather than their ability. They also expressed a need to build their ability to cope with bereavement to help them deal with the death of a parent. People with learning disabilities also highlighted the importance of friendships in building esteem and a sense of safety, and the need to be involved in planning so that their voice is heard and respected.

11. Willis DS, Wishart JG, Muir WJ (2011) Menopausal experiences of women with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 24: 74–85

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This is a moderate quality (+) UK views study which is linked to Willis et al. (2010) (summarised below). While the 2010 paper looked at carer knowledge of the menopause in women with intellectual disabilities, this study directly explored the views and experiences of the women with intellectual disabilities themselves.

Seventy-seven women were originally asked to take part in the study but 11 women refused to take part, 10 women agreed to take part but their carers went on to deny access to the women because they thought being interviewed would worry them unnecessarily. Other carers said that they thought the topic was not appropriate. Six women had to be excluded at the interview stage because of extreme problems with communication and 4 more women were excluded because they were discovered to have had hysterectomies and 1 was excluded because she had dementia.

Forty-five women with intellectual disabilities – 17 with Down's syndrome and 28 without Down's syndrome – were interviewed by a female researcher to find out how much they knew about menopause and its relationship to health and reproduction. Three of the women requested that their carer be present at the interview but the rest were interviewed alone. The women's ages ranged from 35 to 65 and their level of ability ranged between mild, moderate and severe. Based on gatekeeper and carer reports and information that the women gave themselves, the sample had 10 pre-, 15 peri- and 20 post-menopausal women in it.

Findings

Experiences were similar between women with Down's syndrome and those without. Few of the women were able to explain why they had periods, or why they stopped (menopause). Four women responded to the question asking why periods stopped; 2 related it to having or not having babies and the 2 related it to getting older. Most did not respond. Twenty-three women had not heard of the term 'menopause', or 'the change of life', or 'the change', but 17 said they had.

Women's knowledge of menopause symptoms was patchy, with 'hot flushes' being the most common symptom that the women spoke about. Twenty of the 35 peri- and post-menopausal women said that they had experienced them. Seventeen of the women said that they had spoken to someone about their hot flushes: 9 had spoken to staff, 6 had spoken to a doctor or nurse and the others didn't specify.

The women showed little knowledge or understanding of whether other menopause symptoms such as putting on weight, tiredness, mood swings and hair thinning were directly linked to their experience of the menopause or came about because of other causes.

Twenty-four of the women said that they were happy or relieved at the thought (or in some cases, the reality) of their periods stopping. Just 4 women expressed sadness or worry about their periods ending, and 3 felt uncertain.

When asked to describe what going through the menopause was like, those who responded said: ‘feeling funny’, ‘not being pleasant’, or simply spoke about their hot sweats. Four other women said the menopause was a good thing because they no longer had periods.

When asked if they felt they had someone to talk to about the menopause just under 2/3 said they did, most of them would talk to staff or a key worker, but with other support from doctors, family and friends. The vast majority said they would rather talk to another female about ‘women’s problems’.

A simple book or booklet which they could take home and read in private alone or with their carer was the women’s preferred type of health education material.

12. Willis DS, Wishart JG, Muir WJ (2010) Carer knowledge and experiences with menopause in women with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities 7(1): 42–8

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

Willis et al. (2010) is a moderate quality (+) UK views study which explored paid carer knowledge of how the menopause affects women with intellectual disabilities under their care, and how they may support them to cope with this transition. The study is linked to another included study, Willis et al. (2011), which looked at the experiences and knowledge of the menopause of 45 women with intellectual disabilities.

Sixty-nine formal carers working in a range of settings (11 from day care settings and 58 from residential settings) who provided support for the pre-, peri- and postmenopausal women with intellectual disabilities were interviewed on a one-to-one basis for the linked paper. The questions in the interview aimed to find out more about the carers' knowledge and understanding of the menopause and their experiences of supporting women under their care through the menopause. The carers were also asked about what would help them to provide better support for women who are at this transitional stage in their life.

Findings

Although it was difficult to determine whether all of the women with intellectual disabilities had been scanned for breast or cervical cancer or not, the data available showed that the number of women who had been scanned was well under the amount of women who were eligible. Reasons for not applying the cervical smear test were: an assumption of sexual inactivity by the GP, or if the woman's guardian refused permission.

Carers spoke most often about the meaning of the menopause as a life event and also that all women who menstruate – whether or not they have intellectual disabilities – will experience the menopause as part of the natural ageing process. Carers said that they used examples, either of themselves or other women who were older, to help explain to the woman they were caring for that it was natural and that what was happening to them was also happening to other women.

Carers said that they had difficulty separating symptoms and signs of the menopause from other kinds of behaviours that came about through other causes. Just over half of the carers said that they would find it hard to notice any problems that were specific to the menopause. One carer gave the example of a woman she cared for who was 'quite fiery and quite moody' (p45) – it would be hard to know if she was just getting hot and bothered or if she was having a hot flush or mood swings because of the menopause. A minority said that if they knew the woman well then they would notice menopausal symptoms.

Most carers felt that the women they cared for were strong and able to cope with the menopause, in a similar way to how they dealt with other difficulties in their lives. Other carers said that they thought the menopause would be difficult and frightening for them if they did not understand what was going on, or why they had symptoms such as moods and hot flushes.

There were mixed views among the carers about discussing the menopause in relation to fertility and women's ability to have children. The majority believed that if the women were able to understand broadly what it meant, they should be told about the links between menstruation, the menopause and fertility. Some carers expressed concern that this would cause them unnecessary worry.

Although a few carers said it was up to a GP or nurse to talk to the women about the menopause, the majority saw the key worker as the best person. It should be someone that they know and trust, and if the talk was about 'women's problems', then it would be better to be a female.

All carers said they would feel comfortable talking to the women about the menopause but many pointed out the need for better training in order to do this. Symptom identification, advice on explaining the physical changes that happen during menopause, and information on alternatives to hormone replacement therapy were highlighted as useful types of information for carers. Local women's groups or menopause clinics were suggested as useful ways to help the women with intellectual disabilities talk to other women going through the same experience.

Economics

Additional economic analysis was carried out in relation to annual health checks. The full results are reported in Appendix C2. The aim of additional economic analysis was to generate information that would allow a better understanding of the circumstances under which annual health checks could be recommended for this population on cost-effectiveness grounds. More specifically, the objective was to develop a decision-analytic Markov model to estimate long-term health and the economic consequences of annual health checks.

A decision-analytic Markov model was developed, which compared annual health checks versus standard care for this population. It followed hypothetical cohorts of 1000 people in England from when they were 40 years until they died. The type of economic evaluation was cost–utility, that is, effects were expressed in quality-adjusted life years (QALYs) gained and results were presented in incremental cost-effectiveness ratios (ICERs). Costs were assessed from an NHS perspective and expressed in 2016 GBP. In the base case, costs and QALYs were discounted at

3.5%. We carried out probabilistic sensitivity analysis in addition to 1-way sensitivity analysis. Main data sources included: i) IDS-TILDA for the incidence of health conditions in this population; ii) evaluations of annual health checks for information about uptake of annual health checks, health problems identified and referrals initiated; iii) evaluations of the (cost-)effectiveness of treatments for health problems. In addition, Guideline Committee opinion was used to address gaps in evidence. In particular, a number of steps were carried out in close collaboration with the Guideline Committee.

1. The resource inputs that went into annual health checks were estimated; this was based on what the Committee considered good practice; in addition to clinician and nurse time this included the help of a support worker or community learning disability team.

2. Health conditions were selected that were included in the modelling; the focus was on ageing-related conditions and a number of criteria were applied to select conditions; criteria included size of expected impact on costs or outcomes and availability of evidence.

Findings showed that people in the annual health check group had a QALY gain of 0.051 (95% CI 0.049 to 0.0684), and higher lifetime cost of £4,798 (CI 95% £4,787 to £4,971). For a threshold of £30,000 annual health checks were not cost-effective (mean ICER £105,543, 95% CI £103,359 to £140,786). Costs of intervention needed to reduce from an estimated £258 (for annual health checks that followed good practice) to £70 per year in order for annual health checks to be cost-effective.

The modelling was explorative due to the large gaps in evidence. They should be interpreted with caution as their findings are indicative of gaps in knowledge in the following areas in particular: i) prevalence and incidence data of health conditions for this population are not well established (IDS-TILDA is an important exception but also had some limitations); ii) further understanding is needed in regards to identification of ageing-related health conditions in this populations; this includes the training and collaboration required to ensure that health conditions can be identified early and lead to appropriate treatment; iii) more knowledge is needed about the support that people currently get versus what they need to be able to benefit from annual health checks, such as in form of a support worker and additional adjustments.

It is possible that wider system changes are needed in order for annual health checks to lead to better health outcomes at a cost that is justifiable on cost-effectiveness grounds. In the meanwhile ethical and other considerations should lead decision-making. The Guideline Committee agreed that there might also be alternative ways of identifying health conditions and ensure appropriate follow-on support that could be more cost-effective (but this remains currently unknown). No cost-effectiveness studies were identified. As a result of the work the Guideline Committee made a number of research recommendations.

Evidence statements

The evidence statements listed in this section synthesise the key themes across included studies. Note that the following evidence statements refer to both questions 1 and 2 because they report the views of service users or carers and practitioners.

IAR1	There is a small of good quality evidence that practitioners supporting adults with learning disabilities feel they cannot continue to provide care throughout the person's 'old' age. One good quality study (Bigby et al. 2011 ++) found that when a person's medical or personal care needs reached a certain level they would have to move to an aged care environment. The point at which their needs reached this level was subjective and variable and it was hard for families to anticipate.
IAR2	There is a moderate amount of evidence that families and practitioners fail to identify the needs of older people with learning disabilities because they wrongly attribute behaviours and symptoms. The quality of this evidence is moderate. A study by Bowers et al. (2014 +) found that in a group home, delays in seeking care happened because symptoms were wrongly attributed to ageing, dementia or other existing conditions, without alternatives being explored. Another moderate quality study found that services and families attributed behaviour changes in adults with a learning disability to Down's syndrome rather than considering the onset of dementia (Carling-Jenkins et al. 2015 +). A low quality systematic review (Innes et al. 2012 -) found that in generic ageing services changes experienced due to ageing were attributed to a person's learning disability. Needs were therefore not identified. Finally, a UK study of paid care workers (Willis et al. 2010 +) found they had difficulty separating signs and symptoms of the menopause from behaviours resulting from other causes.
IAR3	There is a moderate amount of evidence that older people with learning disabilities and their families are fearful about the future, especially in terms of accommodation, finances, declining health and the provision of care and

	support. The quality of the evidence is mixed. One study by Towers (2013 -) and another by Innes et al. (2012 -) reported high levels of anxiety and fear among parents, particularly around future care and support. A good quality study by Hole et al. (2013 ++) found that adults with learning disabilities were worried about their own future, including being lonely and also about their ageing parents. Family members were anxious about the future financial security of the adult with a learning disability and their ability to make their own choices. Two studies (Bowey and McGlaughlin 2005 +; Dillenburger and McKerr 2011 +) specifically reported panic among adults with learning disabilities when they contemplated their parents' or carers' ill health and death.
IAR4	There is a moderate amount of evidence that despite reported anxiety about the future, families of adults with learning disabilities do not carry out future planning. The quality of the evidence is mixed. The majority of participants in Dillenberger and McKerr (2011 +) had not discussed future provision of care and support with social services and avoided discussion within their families at the risk of causing distress. Similarly, only a minority of parents in another study (Towers 2013 -) had spoken to practitioners about future planning. Families with relatives in group homes had clearly not considered future planning (Bigby et al. 2011 ++) and in Innes et al. (2012 -) families and supporters were unwilling or unable to undertake forward planning.
IAR5	There is some evidence that future housing needs are a key worry for adults with learning disabilities and their families. Overall the quality of the evidence is moderate. In the low quality Towers study (2013 -) over 80% of parents were extremely worried or worried about whether, in the future, their son or daughter would have a place to live where they were happy. Ageing adults with learning disabilities were also reportedly worried about their future living arrangements (Hole et al. 2013 ++). In a moderate quality study, despite the stress of thinking about a future without their parents, ageing adults with a learning disability had clear preferences for their future housing. The availability of local support and remaining in their local area were high priorities (Bowey and McGlaughlin 2005 +). Finally, according to Innes et al. (2012 -) practitioners and families were worried about the prospect of independent living for the adult with a learning disability because they felt there were associated risks.
IAR6	There is some evidence that planning for the future of older people with learning disabilities should involve the whole family, including the person themselves. A moderate quality study by Coyle et al. (2014 +) highlighted the importance of future planning with regard to the sibling role. Siblings said they needed to plan for a situation in which their parents could no longer provide care. Where parents had made future plans, a moderate quality study (Dillenberger and McKerr 2011 +) reported that they involved transferring the family home and caring responsibilities to non-learning-disabled children. On the other hand, parents interviewed in a good quality study (Hole et al. 2013 ++) said they did not want their other children to be 'burdened' with caring for their sibling. The results of this study point to the importance of early planning that balances the needs and desires of ageing adults with learning disabilities and family members. Finally, Bowey and McGlaughlin (2005 +) found that in situations of 'mutual caring', adults with learning disabilities were reluctant to move away to shared accommodation out of concern for how their parents will cope. This highlights that the line between carer and cared for is often blurred and everyone's wishes and needs must be considered during future planning.

Included studies for these review questions

For review questions 1 and 2

Bigby C, Bowers B, Webber R (2011) Planning and decision making about the future care of older group home residents and transition to residential aged care. Journal of intellectual disability research 55: 77–89

Bigby C, Webber R, Bowers B (2015) Sibling roles in the lives of older group home residents with intellectual disability: working with staff to safeguard wellbeing. Australian Social Work 68: 453–68

Bowers B, Webber R, Bigby C (2014) Health issues of older people with intellectual disability in group homes. Journal of Intellectual and Developmental Disability 39: 261–9

Carling-Jenkins R, Torr J, Iacono T et al. (2012) Experiences of supporting people with Down syndrome and Alzheimer's disease in aged care and family environments. Journal of intellectual and developmental disability 37: 54–60

Bowey L, McGlaughlin A (2005) Adults with a learning disability living with elderly carers talk about planning for the future: aspirations and concerns. The British Journal of Social Work 35: 1377–92

Coyle CE, Kramer J, Mutchler JE (2014) Aging together: sibling carers of adults with intellectual and developmental disabilities. Journal of Policy and Practice in Intellectual Disabilities 11: 302–12

Dillenburger K, McKerr L (2011) 'How long are we able to go on?' Issues faced by older family caregivers of adults with disabilities. British Journal of Learning Disabilities 39: 29–38

Hole RD, Stainton T, Wilson L (2013) Ageing adults with intellectual disabilities: self-advocates' and family members' perspectives about the future. Australian Social Work 66: 571–89

Innes A, McCabe L, Watchman K (2012) Caring for older people with an intellectual disability: a systematic review. Maturitas 72: 286–95

Towers C (2013) Thinking ahead: improving support for people with learning disabilities and their families to plan for the future. London: Foundation for People with Learning Disabilities

Willis DS, Wishart JG, Muir WJ (2011) Menopausal Experiences of Women with Intellectual Disabilities. Journal of Applied Research in Intellectual Disabilities 24: 74–85

Willis DS, Wishart JG, Muir WJ (2010) Carer knowledge and experiences with menopause in women with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities 7(1): 42–8

3.2 Information, advice and training for older people with learning disabilities

Introduction to the review questions

Review question 3, comprised of parts a, b and c, is reported in this sub-section. Part a sought data about the acceptability, effectiveness and cost-effectiveness of providing information, advice and training to older people with learning disabilities. Part b was designed to locate the self-reported views and experiences of older people with learning disabilities, their families, carers and advocates about information, training and advice available to them, including what works and what does not work well. Finally, part c sought the views and experiences of people delivering, organising and commissioning social care, health and housing services about information, training and advice available to older people with learning disabilities. This included views on what works and what does not work well.

Review questions

3a. What is the acceptability, effectiveness and cost-effectiveness of providing information, advice and training to older people with learning disabilities?

3b. What are the views and experiences of older people with learning disabilities and their carers about information, advice and training to older people with learning disabilities?

3c. What are the views and experiences of health, social care and other health practitioners about information, advice and training to older people with learning disabilities?

Summary of the review protocol

The protocol sought to identify studies that would:

- Identify the acceptability, effectiveness and cost-effectiveness of providing information, advice and training to older people with learning disabilities, their families, carers and advocates.
- Identify emerging models and approaches to improving information, advice and training for older people with learning disabilities, their families, carers and advocates and the associated outcomes.
- Describe the self-reported views and experiences of older people with learning disabilities, their families, carers and advocates about information, training and advice available to them, including what works and what does not work well.
- Describe the views and experiences of people delivering, organising and commissioning social care, health and housing services about information, training and advice available to older people with learning disabilities, their families, carers and advocates. Includes views on what works and what does not work well.

Population

Older people with learning disabilities, their families and carers.

Social care practitioners (providers, workers, managers, social workers), housing practitioners and health and social care commissioners involved in delivering care and support at home to older people with learning disabilities.

Intervention

Information, advice and training for families, carers and advocates of older people with learning disabilities.

Setting

People’s own homes, family homes and temporary accommodation such as hostels and respite arrangements; supported living, residential and nursing care homes (including hospices). Primary healthcare, outpatients and community hospitals.

Outcomes

Person-focused outcomes (independence, choice and control over daily life; capability to achieve desired person-centred outcomes; user and carer satisfaction; continuity of care; health and social care-related quality of life, including carer quality of life; years of life saved) and service outcomes (use of health and social care services and housing support; need for support from health and social care practitioners and carers; delayed transfers of care from hospital; hospital admissions and readmissions; admission to care homes; length of stay in hospital and care homes). See 1.6 in the scope.

Study design

The study designs relevant to these questions were expected to include: systematic reviews of studies of different models of discharge assessment and care planning; randomised controlled trials (RCTs) of different approaches to discharge assessment and care planning; economic evaluations; quantitative and qualitative evaluations of different approaches; observational and descriptive studies of process; cohort studies, case control and before and after studies; mixed methods studies.

The study designs which were prioritised for the views and experiences questions included: systematic reviews of qualitative studies on this topic; qualitative studies of user and carer views of social and integrated care; qualitative components of effectiveness and mixed methods studies and observational and cross-sectional survey studies of user experience.

See Appendix A for full protocols.

How the literature was searched

One single search was conducted for all but 1 of the review questions (RQ 8: End of life care). Electronic databases in the research fields of health (including mental health), social care, social science and economics were searched using a range of controlled indexing and free-text search terms. Additional searches of websites of relevant organisations, and trials registries, were undertaken to capture literature that may have been missed from the database searches. The search was based upon 2 concepts: a) older people, ageing and future planning, or aged care services; and b) intellectual or learning disabilities.

A wide range of search terms were used to find these 2 concepts. The search terms were developed from various methods. This included finding 52 items that related to the topic, and discovering relevant search terms.

See Appendix A for full details of the search.

How studies were selected

Search outputs (title and abstract only) were stored in EPPI Reviewer 4 – a software program developed for systematic review of large search outputs. Coding tools were applied and all papers were screened on title and abstract. Formal exclusion criteria were developed and applied to each item in the search output, as follows:

- Language (must be in English).
- Population. (For question 3b, must be about older people with learning disabilities, their families or supporters. Note that in line with the scope, a specific age limit will not be used to define older people so a flexible and pragmatic approach to screening on the target population will be taken. For question 3c, must be about social care practitioners involved in delivering care and support at home to older people with learning disabilities.)
- Intervention (must be about providing information, advice and training to older people with learning disabilities).
- Setting. (Must be people's own homes, family homes and temporary accommodation such as hostels and respite arrangements; supported living, residential and nursing care homes, including hospices. Primary healthcare, outpatients and community hospitals.
- Country (must be UK or other OECD).
- Date (must not be published before 2005).
- Type of evidence (must be research).

Title and abstract of all research outputs were screened against these exclusion criteria. Those included at this stage were marked for relevance to specific review questions and retrieved as full texts.

Full texts were again reviewed for relevance and research design. A list of studies excluded on full text can be found in Appendix A, organised by exclusion criteria.

If still included, critical appraisal (against NICE tools) and data extraction (against a coding set developed to reflect the review questions) was carried out. The coding was all conducted within EPPI Reviewer 4, and formed the basis of the analysis and evidence tables. All processes were quality assured by double coding of queries, and of a random sample of 10%.

See Appendix B for full critical appraisal and findings tables.

Overview of evidence

In our initial screen (on title and abstract) we found 22 studies which appeared relevant to review question 3. We retrieved and reviewed full texts and included 5 papers and then in the update search another paper was located (Whitehead et al. 2016 ++), bringing the total to 6 papers. The internal validity of the evidence was good to moderate. Only 1 effectiveness study was found, although results were of limited use. No cost-effectiveness studies were found. The views and experiences of older people with learning disabilities and their families were well represented but only 1 study provided the practitioner perspective. The views studies provided important information about what works and what does not work in providing information. There was a particular lack of evidence trialling approaches or interventions, and a gap in evidence about training for older people with learning disabilities, whether it is needed and how best to provide it.

Narrative summary of the evidence

In this section, a narrative summary of each included study is provided, followed by a synthesis of the evidence, according to the key outcomes, themes or sub-groups in the form of evidence statements (p84). The approach to synthesising evidence was informed by the PICO within the review protocol.

Please note that the following studies provide data to help answer parts a, b and c of question 3.

a) Acceptability and effectiveness

1. Van Puyenbroeck J, Maes B (2009) The effect of reminiscence group work on life satisfaction, self-esteem and mood of ageing people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 22: 23–33

Methods: Quasi-experimental quantitative

Data: Effectiveness

Country: Belgium

Outline

This study from Belgium was judged to be of moderate quality (+) and moderately relevant to the review question (+). The authors wanted to test how good a 'narrative reminiscence' programme was at making older people with learning disabilities feel positive about their lives. Narrative reminiscence programmes involve asking people to think and talk about the important events in their past that have affected them and made them who they are now. They met with 41 people with learning disabilities every week for 12 weeks. On half of these occasions they did narrative reminiscence during the session, while for the other half of sessions they did something else.

At the end of every session they were asked about how satisfied they were with their life, how capable they felt they were in life and how happy and interested they felt with life. Also at the start of the study they were also asked about how good their memory usually is, and about their personality.

Findings

Overall, the narrative reminiscence sessions did not make people feel any different about how satisfied (Life satisfaction [SATISF], F= 2.20; p=0.15) or how capable they felt with their life (General perceived competence [COMPET], p=0.21; Perceived cognitive competence [COMPET C], F= 0.15; p=0.69; Perceived physical competence [COMPET M], F= 2.10, p=0.15; Perceived social acceptance by family/ social support workers [COMPET S1], F=3.03; p=0.09; and Perceived social acceptance by peers [COMPET S2], F=1.80; p=0.18), compared to the other sessions. Between the first and the last seesions, the effect size was medium (Cohen's d=0.74). The participants did feel happier as the sessions went by, however they felt happier regardless of whether it had been the narrative reminiscence sessions or the other sessions they had done.

How happy they felt as a result of the sessions was affected by how outgoing and how emotionally stable they were generally.

Although it didn’t appear to help their mood, they did say they enjoyed getting to do the sessions and didn’t find them scary or boring.

b) Views of older people with learning disabilities/their carers and supporters

2. Cardol M, Rijken M, van Schrojenstein Lantman-de Valk H (2012) People with mild to moderate intellectual disability talking about their diabetes and how they manage. Journal of Intellectual Disability Research 56: 351–60

Methods: Qualitative

Data: Views and experiences

Country: The Netherlands

Outline

This qualitative study from the Netherlands was well conducted (++) and its findings could be generalised moderately well to our setting and question (+). They interviewed 17 people with mild to moderate learning disabilities and diabetes. They aimed to investigate their experiences of diabetes and what factors are related to their self-management of the condition. The interviews were conducted at home, asking some set questions about particular topics but allowing plenty of room for the participants to elaborate in their answers. Initially they had 24 people to interview, but after 17 they stopped because no new information or themes were appearing in the data.

Findings

The findings fell under 7 themes. Four of them had some insight which relates in some way to training and advice, or the need for it.

Unanswered questions (theme 4)

Many participants had questions about diabetes, which had gone unanswered, such as ‘Can I get rid of it?’ and ‘Will I live long?’ Unanswered questions were coupled with concerns and fearful thoughts. To feel better they often reported trying not to think about it.

Check-ups without questioning (theme 5)

Even though they had questions, participants said they rarely asked them, for example when at check-ups with doctors. It was suggested that this might due to expecting that the answer wouldn’t be given to them in a way they would be able to understand. Having a trusted adult with them to ask questions and relay the answers later was helpful here.

Intentions to self-manage are related to understanding, motivation and special occasions (theme 6).

None of them had received written diabetes information in a way they could understand. They relied heavily on relatives for information.

Self-management is related to feelings of self-efficacy, support, health condition, mood and contextual factors (theme 7).

Self-management requires confidence as well as understanding. However, confidence needs to be developed. In quite sheltered environments like community housing they were often ‘overseen’ rather than given the chance to learn to do it for themselves.

3. Willis DS (2008) A decade on: what have we learnt about supporting women with intellectual disabilities through the menopause? Journal of Intellectual Disabilities 12: 9–23

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This qualitative study from the UK was moderately well conducted (+) and its findings were moderately relevant to our setting and question (+). The researchers interviewed 18 older women with learning disabilities who had stopped having monthly periods. They aimed to investigate the women's understanding of why their period had stopped and look at what information was available to them. The interviews were conducted one-on-one, without carers, as this might influence what the participants said. The interviews were held at a place chosen by the participants, and they were asked set questions about particular topics but allowing plenty of room for them to elaborate in their answers.

Findings

Some parts of the findings included discussion about advice and training, or the lack of it.

Twelve of the 18 women had received no information or help about the menopause. Three had heard some information through the television.

The participants had no strong feelings about whether more information would be useful. The authors suggested this was because they were used to being told what was best to do, and due to a struggle to come up with questions and ask for advice.

It was concluded that there is a lack of information on menopause available to older women with learning disabilities in an appropriate format. They also felt there was stigma in general towards this group about discussing any topics related to reproduction.

4. Young AF, Naji S, Kroll T (2012) Support for self-management of cardiovascular disease by people with learning disabilities. Family Practice 29: 467–75

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This qualitative study from the UK was well conducted (++) and its findings were very relevant to our setting and question (++). The researchers interviewed 14 people with learning disabilities and heart problems, plus 11 care staff and 11 health practitioners. They aimed to investigate (1) how heart problems were managed, (2) how carers and health staff supported this, and (3) what further support was needed. The interviews were conducted face-to-face, asking set questions about particular topics but allowing plenty of room for the participants to elaborate in their answers. For the participants with learning difficulties, the questions were made more clear using pictures and relatable story examples that others had helped to develop.

Findings

The findings included 4 themes, which related to training and advice, or the need for it.

Strategies for using knowledge and creating routines

Health messages about food and exercise are commonly known, including to people with learning disabilities. This knowledge makes a great start to build upon.

Some popular ways to encourage health behaviours included:

- increments – introduce changes bit by bit with small increases
- socialiation – work it into something social that the person already likes (for example, football, playing pool)
- substitution – using healthy versions of things they already like.

Steps to improve health behaviour must be coordinated across everyone they know. For example, healthy eating doesn't work if carers do a healthy shop but then siblings visit with a large bag of sweets.

Understanding the prerequisites for self-management support

The person themselves must be involved in any changes, and conversations need to be pitched in a way that's meaningful to them. Changes work best when the person themselves owns them. Include a plan for rewards and occasional exceptions.

Primary and secondary supporters of self-management

Carers play the biggest part in support. However, although health professionals are more distant, people with learning disabilities still highly value their knowledge and authority. Health professionals underestimate their part in the process, but it should not be overlooked.

Self-management implementation

Turning something from a plan into a reality was the hardest part, taking energy and discipline. Knowledge is vital, but practical support is needed too.

c) Views of practitioners

5. Willis DS, Wishart JG, Muir WJ (2010) Carer knowledge and experiences with menopause in women with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities 7(1) 42–8

Method: Qualitative

Data: Views and experiences

Country: UK

Outline

This is a moderate quality UK-based study (+), which explored paid carers' knowledge of how menopause affects women with intellectual disabilities under their care, and how they may support them to cope with this transition. The study is linked to another views study, Willis et al. (2011). Sixty-nine formal carers working in a range of settings (11 from day care settings and 58 from residential settings) who provided support for the pre-, peri- and postmenopausal women with intellectual disabilities were interviewed. The interviews aimed to find out about the carers' knowledge and understanding of the menopause and their experiences of supporting women under their care through the menopause. The carers were also asked about what would help them to provide better support. Some of the findings are relevant to information needs and provision.

Findings

The staff spoken to all had similar training backgrounds and levels of formal qualification. The carers interviewed spoke of difficulties in communicating the effects of menopause and female health to older people with learning difficulties. Most carers said that they felt comfortable talking to women about their health and the menopause but would like better training if this was to become part of their role regularly. Most carers reported a good knowledge of the menopause, but some staff showed poor knowledge of menopause; 1 interviewee confused menopause with menstruation.

Training and information needs identified by carers included: symptom identification, advice on explaining the physical changes that happen during menopause and information on alternatives to hormone replacement therapy were highlighted as useful types of information for carers. Local women’s groups or menopause clinics were suggested as useful ways to help the women with learning disabilities talk to other women going through the same experience. Other recommended information formats were talking books, videos and booklets, and talks from specialised health practitioners.

6. Whitehead LC, Trip HT, Hale LA et al. (2016) Negotiated autonomy in diabetes self-management: the experiences of adults with intellectual disability and their support workers. Journal of Intellectual Disability Research 60: 389–97

Method: Qualitative

Data: Views and experiences

Country: New Zealand

Outline

This good quality study (++) was judged to be moderately relevant to the review question (+). The study aimed to explore how people with learning disabilities who have diabetes are able to exercise autonomy in managing this condition, through a process of negotiation with support staff. There were interviews with 14 people with learning disabilities, and with 17 support workers who work with them. The people with learning disabilities were aged between 23 and 69, with a mean age of 50.9 years. Eleven were identified as having a mild learning disability, and 3 with a moderate learning disability. Six were female and 8 male, 8 had type 1 diabetes and

6 had type 2 diabetes. They are described as a ‘convenience sample’, specifically recruited through primary health providers and disability services.

All the interviews, which were semi-structured, were carried out by a single member of the research team, a nurse who had more than 20 years’ clinical experience in the field of learning disability.

Findings

Analysis of the data from the interviews generated 3 themes about the way in which self-management of diabetes is negotiated in different circumstances.

1. The first theme was ‘negotiated autonomy on a day to day basis’. The activities this included were blood glucose monitoring, food choices and medication. All participants with learning disabilities described initiating and carrying out their own blood glucose tests, but most found recording the results challenging. They showed that they knew how to complete the test, and knew what a high or low score would look like. About half were doing this 3-4 times a day independently.

Participants with learning disabilities managed their own tablet medication, although they might be supported periodically. Insulin was also mostly self-administered, but with practitioner oversight. Staff would be involved where additional insulin was being taken due to hyperglycaemia. Although administering medication, including additional medication based on the blood glucose reading, was seen by all as a negotiated process, the study reported that the person with learning disabilities was directing the process and being supported to do so safely.

Maintaining a healthy diet was seen as being the most challenging area, with participants with learning disabilities describing their difficulties in avoiding sweet and fatty foods. Support workers discussed strategies together with participants on dietary choices and provided encouragement and reminders about shopping, cooking, eating out and snacking, in a process described as ‘negotiated, ongoing and supportive rather than contested’ (p392).

Building up trust between participants with learning disabilities and their support workers was seen as being key to being open and honest about blood glucose levels and symptoms experienced.

An example was given of a different, more didactic approach not working so well. A participant with learning disabilities had missed appointments at a diabetes clinic because of feeling pressured by doctors over weight gain.

Support worker participants discussed identifying benefits and risk, which meant respecting the person’s right to make decisions about their own lives, even if they sometimes made poor choices.

2. The second theme was ‘renegotiation of autonomy in times of transition’, which referred to periods of ill health or of change in accommodation or treatment regime. The study found an expectation that the person would still manage their diabetes as independently as possible during these times, for example when 1 participant was changing her medication regime and so needed to test her blood glucose more often, it was observed that she remained in control of testing. Another participant with serious health concerns was able to call on staff for extra help when he thought he needed it.

3. The third theme was ‘renegotiation of autonomy in relation to goals’. This referred to greater autonomy being negotiated with support workers, with the aim of increasing independence in daily living for the person with a learning disability. For example, staff were seeking a flatmate to share the cooking with 1 participant who wanted to live more independently, while also supporting her to manage insulin more independently, so that she could manage with less oversight. Another was supported to maintain a healthier diet by being helped to find alternative work to the fast food outlet where he was employed, where the unhealthy food that was available was having an impact on his diet and food choices.

The researchers observed that the ‘process of negotiation was fluid, responding to situational events such as changes in health or medication regime, and during these times, autonomy was renegotiated. The process of negotiated autonomy was evident across level of impairment, health status, glycated haemoglobin levels, living situation and age’ (p394).

Economics

No cost-effectiveness studies were identified and no additional economic analysis was undertaken for this review question.

Evidence statements

The evidence statements listed in this section synthesise the key themes across included studies.

IAT1	There is a moderate amount of evidence that advice about health experiences is not always presented clearly enough for older people with learning disabilities. This leads to confusion and a lack of understanding. The quality of this evidence is moderate to good. A study from the Netherlands (Cardol et al. 2012 ++) found that not 1 of the participants had received written information about their health condition (diabetes) in a way they could understand (p3). A UK study by Willis (2008 +) also found that 12 out 18 respondents had received no information about the menopause and for 3 women the television had been their source of information. Any information that had been provided was produced in an inappropriate format (p4). Another UK study by Young et al. (2012) emphasised that information for older people with learning disabilities needs to be presented in a meaningful way so they can manage their heart condition (p6). Finally, Willis et al. (2010 +) found that care workers wanted specific training to help them communicate with older women with learning disabilities and provide them with advice and support through the menopause (p8).
IAT2	There is a moderate amount of evidence that older people with learning disabilities need to be better supported to manage their own health conditions. The quality of the evidence is mainly good. The study by Cardol et al. (2012 ++) found that older people with learning disabilities needed support to become more confident and have greater understanding so they could self-manage their diabetes (p3). The New Zealand study by Whitehead et al. (2016 ++) showed that with support and through negotiation, adults with mild to moderate learning disabilities can manage their own diabetes, even in difficult areas such as maintaining a healthy diet, which required encouragement and timely reminders from support staff. A UK study by Willis (2008 +) found that the older women in the study had no experience of involvement in managing the menopause and this may be due to the fact that they are used to being told what is best for them. They were reluctant to ask questions or discuss what was happening to them (p4). The study by Young (2012 ++) found that older people with learning disabilities needed more practical support to be able to manage their heart condition and that changes to their lifestyle would be far easier to achieve if they were actively involved in planning (p6).
IAT3	There is a small amount of evidence that family and carers play a central role in supporting and advising older people with learning disabilities about their health conditions. The quality of the evidence is good. The study by Cardol et al. (2012 ++) found that it is very important for older people with learning disabilities to have a trusted adult with them during medical check-ups. The role of the trusted adult includes asking questions of doctors and afterwards explaining the answers in a way the person can understand (p3). The study by Young (2012 ++) confirmed that families and carers play the biggest part in supporting older people with learning disabilities to manage their heart condition. It is important to note that family support and support from staff needs to be well coordinated so that the actions of 1 do not undermine plans made by the other. The example of healthy eating is given in the study (p6).
IAT4	There is a small amount of evidence that explains how best to communicate health messages to older people with learning disabilities. The quality of the evidence is moderate to good. The UK study by Young (2012 ++) found that

	changes to health behaviours should be introduced bit by bit and worked into social activities that the person already enjoys (e.g. playing football or going for walks) (p6). The Willis study (2010 +) recommended that to give advice about the menopause, women's groups or menopause clinics could be useful and that information should be given in accessible formats such as talking books, videos or booklets (p8).
IAT5	There is a small amount of evidence that practitioners could play a greater role in providing advice and support about health issues to older people with learning disabilities. The quality of the evidence is moderate to good. The UK study by Young (2012 ++) found that older people with learning disabilities really value the medical knowledge and authority of health professionals. However, health professionals themselves often do not recognise the important contribution they can make in supporting people to manage their conditions (p6). The Willis study (2010 +) reported that care workers wanted more training so that they would be able to provide better support and advice to older women with learning disabilities while they experience the menopause (p8).
IAT6	There is a small amount of evidence about the effectiveness or cost-effectiveness of training programmes or support for older people with learning disabilities. Puyenbroeck and Maes (2009 +) conducted a study to test a reminiscence programme to improve the quality of life of older people with learning disabilities. Although participants enjoyed the sessions, the study found that people were just as happy with another programme, which did not include reminiscence. The design of the study also makes it difficult for us to have confidence in the findings (p1).

Included studies for these review questions

Cardol M, Rijken M, van Schrojenstein Lantman-de Valk H (2012) People with mild to moderate intellectual disability talking about their diabetes and how they manage. Journal of Intellectual Disability Research 56: 351–60

Van Puyenbroeck J, Maes B (2009) The effect of reminiscence group work on life satisfaction, self-esteem and mood of ageing people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 22: 23–33

Whitehead LC, Trip HT, Hale LA et al. (2016) Negotiated autonomy in diabetes self-management: the experiences of adults with intellectual disability and their support workers. Journal of Intellectual Disability Research 60: 389–97

Willis DS (2008) A decade on: what have we learnt about supporting women with intellectual disabilities through the menopause? Journal of Intellectual Disabilities 12: 9–23

Willis DS, Wishart JG, Muir WJ (2010) Carer knowledge and experiences with menopause in women with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities 7(1) 42–8

Young AF, Naji S, Kroll T (2012) Support for self-management of cardiovascular disease by people with learning disabilities. Family Practice 29: 467–75

3.3 Information, advice, training and support for families, carers and advocates of older people with learning disabilities

Introduction to the review questions

Review question 4, comprised of parts a, b and c, is reported in this sub-section. Part a sought data about the acceptability, effectiveness and cost-effectiveness of providing information, advice and training to the families and carers of older people with learning disabilities and also about any emerging models in this area. Part b was designed to locate the self-reported views and experiences of older people with learning disabilities and their carers about information, training and advice for families, carers and advocates of older people with learning disabilities, including what works and what does not work well. Finally, part c sought the views and experiences of people delivering, organising and commissioning social care, health and housing services about information, training and advice for families, carers and advocates. This included views on what works and what does not work well.

Review questions

4a. What is the acceptability, effectiveness and cost-effectiveness of providing information, advice, training and support for families, carers and advocates of older people with learning disabilities?

4b. What are the views and experiences of older people with learning disabilities and their carers about information, advice, training and support provided to families, carers and advocates?

4c. What are the views and experiences of health, social care and other practitioners about information, advice, training and support for families, carers and advocates?

Summary of the review protocol

The protocol sought to identify studies that would:

- Identify the acceptability, effectiveness and cost-effectiveness of providing information, advice and training to older people with learning disabilities, their families, carers and advocates.
- Identify emerging models and approaches to improving information, advice and training for older people with learning disabilities, their families, carers and advocates and the associated outcomes.
- Describe the self-reported views and experiences of older people with learning disabilities, their families, carers and advocates about information, training and advice available to them. This includes what works and what does not work well.

Population

Older people with learning disabilities, their families, carers and advocates.

Social care practitioners (providers, workers, managers, social workers), housing practitioners and health and social care commissioners involved in delivering care and support at home to older people with learning disabilities.

Intervention

Information, advice and training for families, carers and advocates of older people with learning disabilities.

Setting

People’s own homes, family homes and temporary accommodation such as hostels and respite arrangements; supported living, residential and nursing care homes (including hospices). Primary healthcare, outpatients and community hospitals.

Outcomes

Person-focused outcomes (independence, choice and control over daily life; capability to achieve desired person-centred outcomes; user and carer satisfaction; continuity of care; health and social care-related quality of life, including carer quality of life; years of life saved) and service outcomes (use of health and social care services and housing support; need for support from health and social care practitioners and carers; delayed transfers of care from hospital; hospital admissions and readmissions; admission to care homes; length of stay in hospital and care homes). See 1.6 in the scope.

Study design

The study designs relevant to the ‘effectiveness and cost-effectiveness’ part of this question included: systematic reviews of studies of interventions to provide information, advice and training for older people with learning disabilities, their families, carers and advocates; randomised controlled trials (RCTs) of interventions to provide information, advice and training for older people with learning disabilities, their families, carers and advocates; economic evaluations; quantitative and qualitative evaluations of different approaches; observational and descriptive studies of process; cohort studies, case control and before and after studies; mixed methods studies.

The study designs relevant to the views and experiences parts of this question included: systematic reviews of qualitative studies on this topic; qualitative studies of user, carer and practitioner views about providing information, advice and training for older people with learning disabilities, their families, carers and advocates; qualitative components of effectiveness and mixed methods studies; observational and cross-sectional survey studies of user or carer experience.

See Appendix A for full protocols.

How the literature was searched

One single search was conducted for all but 1 of the review questions (RQ 8: End of life care). Electronic databases in the research fields of health (including mental health), social care, social science and economics were searched using a range of controlled indexing and free-text search terms. Additional searches of websites of relevant organisations, and trials registries were undertaken to capture literature that may have been missed from the database searches. The search was based upon 2 concepts: a) older people, ageing and future planning, or aged care services; and b) intellectual or learning disabilities.

A wide range of search terms are used to find these 2 concepts. The search terms were developed from various methods. This included finding 52 items that related to the topic, and discovering relevant search terms.

See Appendix A for full details of the search.

How studies were selected

Search outputs (title and abstract only) were stored in EPPI Reviewer 4 – a software program developed for systematic review of large search outputs. Coding tools were applied and all papers were screened on title and abstract. Formal exclusion criteria were developed and applied to each item in the search output, as follows:

- Language (must be in English).
- Population. (For question 4b, must be about older people with learning disabilities, their families or supporters. Note that in line with the scope, a specific age limit will not be used to define older people so a flexible and pragmatic approach to screening on the target population will be taken. For question 4c, must be about social care practitioners involved in delivering care and support at home to older people with learning disabilities.)
- Intervention (must be about providing information, advice and training to families carers, and advocates of older people with learning disabilities).
- Setting. (Must be people's own homes, family homes and temporary accommodation such as hostels and respite arrangements; supported living, residential and nursing care homes, including hospices. Primary healthcare, outpatients and community hospitals.
- Country (must be UK or other OECD).
- Date (must not be published before 2005).
- Type of evidence (must be research).

Title and abstract of all research outputs were screened against these exclusion criteria. Those included at this stage were marked for relevance to specific review questions and retrieved as full texts.

Full texts were again reviewed for relevance and research design. A list of studies excluded on full text can be found in Appendix A, organised by exclusion criteria.

If still included, critical appraisal (against NICE tools) and data extraction (against a coding set developed to reflect the review questions) was carried out. The coding was all conducted within EPPI Reviewer 4, and formed the basis of the analysis and evidence tables. All processes were quality assured by double coding of queries, and of a random sample of 10%.

See Appendix B for full critical appraisal and findings tables.

Overview of evidence

In our initial screen (on title and abstract) we found 20 studies which appeared relevant to review question 4. We retrieved and then reviewed full texts and included a total of 4 papers. The studies, all providing data about the views and experiences of older people with learning disabilities and their families, were judged to be of moderate quality. They focused on gaps in information, training and support needs for carers of older people. There was a lack of evidence trialling approaches/interventions, and a gap in evidence about training programmes for older people with learning disabilities, in terms of how best to provide those and how (cost)-effective they were. Finally, there was no evidence about the views of practitioners (for question 4c) and no evidence relating to effectiveness or cost-effectiveness (for question 4a).

Narrative summary of the evidence

In this section, a narrative summary of each included study is provided, followed by a synthesis of the evidence, according to the key outcomes, themes or sub-groups in the form of evidence statements (p77). The approach to synthesising evidence was informed by the PICO within the review protocol.

The following studies provide data about information, advice, training and support for families, carers and advocates of older people with learning disabilities. Only data related to part b of the question were located and are presented below.

a) Acceptability and effectiveness – no data located

b) Views of older people with learning disabilities/ their carers and supporters

1. Furniss KA, Loverseed A (2012) The views of people who care for adults with Down's syndrome and dementia: a service evaluation. British Journal of Learning Disabilities 40: 318–27

Method: Qualitative

Data: Views and experiences

Country: UK

Outline

This study was judged to have good relevance to the review area (++) and to be of moderate quality (+). The study is a qualitative paper based on 13 interviews with family carers or practitioners supporting individuals with dementia and Down's syndrome. The study aimed to find out the views of carers and practitioners about their information, support and training needs about dementia in people with Down's syndrome. The services the carers were receiving, or that practitioners were delivering are not clear and there was no follow up, but the study does provide good insight into the information needs of carers and practitioners working with this group. However, given that the review question only focuses on the training and support needs of families and carers (rather than practitioners), only their data are reported to the Guideline Committee.

Findings

The study identifies 3 main themes: knowledge and information, coping and support, and concerns about the future.

Knowledge and information

Families and carers said they only became aware of the link between Down's syndrome and dementia when the diagnosis was received. Families and carers also said that they had little information about how the condition would progress and what services they could access. They wanted to know more about the relationship between Down's syndrome and dementia: 'We're completely blank and it would be nice to know something about it' (p323).

Some carers felt that lack of information available led them to rely on informal sources of information, like word of mouth, which had sometimes led to confusion and misunderstanding: ‘I only know that they can’t communicate, but I don’t know much about it’ (p323).

Families and carers said that they had begun to realise that there was information available, but it was not known about: ‘you don’t realise there is so much out there, you really, really don’t. And unless you’re told, you won’t’ (p323).

All families and carers said that they did not have enough information about the duration of the illness or the process of the disease: ‘He [consultant psychiatrist] wouldn’t tell me how long it would be … because people vary, it could be one or two years … I didn’t quite know whether that meant he would be bad in two years or quite what’ (p323).

All interviewees said that they lacked information about the impact of the condition on a person with Down’s syndrome.

Coping and support

The study found mixed feelings among carers about support they had received from services and professionals. Negative past experience impacted on propensity to seek support. ‘I don’t want to go to social services or anybody unless I really have to because I’m now labelled because I’ve been through two complaints to get her the care she deserves …’ (relative)’ (p324).

Carers said that they had seen a lot of professionals and some said that they valued support that was based on relationships, built up over time. Others didn’t know when to ask for help: ‘when do you start shouting for help?’ (p324).

Both staff and carers said that it was important to include relatives and family carers in planning care and support and keeping them informed. Some carers reported feeling excluded from care.

Concerns about the future

Interviewees were asked which services they were currently receiving and what they would be interested in receiving in the future.

Family carers requested dementia information in a printed format, and one-to-one explanation of dementia with a professional. Advice on communication strategies was another need, as were support groups, information sessions and advice about behaviours and activities.

2. Janicki MP, Zendell A, DeHaven K (2010) Coping with dementia and older families of adults with Down syndrome. Dementia 9: 391–407

Method: Qualitative

Data: Views and experiences

Country: USA

Outline

This qualitative study used a sample of 17 parents and relatives of adults with Down's syndrome and dementia. The study aimed to find out the effect of caregiving on family carers and levels of care provided. The study contains some information on support and carers accessing outside help or training to deal with escalating needs. The study is assessed as having a moderate level of relevance to the guideline and review question (+) and a moderate level of methodological quality (+). The study used a variety of tools to measure impact on carers including: Modified Caregiver Strain Index, Caregiver Burden Survey, Caregiver Concern Survey, Family Health Status Inventory and the Caregiver Activity Survey-Intellectual Disabilities (CAS-ID).

Findings

The relevant findings relate to decision-making around future care and adaptation to the home environment.

Decision-making

Most carers made the decision to care for the adult at home and few sought staff or agency help with this decision. Most respondents said that they planned to seek a doctor or specialist's advice around future care, when things became challenging. They said they would seek personal care assistance or the help of a sibling and some said they would look for help from a professional 'treatment team'.

The ability of the adult to remain in the home was felt to be dependent on their own ability to care in the first instance, increased medical needs of the individual and also the level of support available from other family members or the availability of services to meet heightened needs.

Changes to the home environment

Carers sought help with caring tasks in a number of ways: 23.5% received respite help, 11.8% looked for training on special care and 5.9% got part time help in the home; 41.2% received no extra help.

Some carers found it hard to find appropriate support, even if they had financial assistance to pay for it. One parent reported that she had received governmental financial support for respite but could not find anyone to provide it. Carers reported gradual changes in the needs of their son or daughter and for some this meant staff assistance or obtaining adaptive equipment in the home. Carers noted 'unmet needs from respite services, nutritional assistance and speech therapy' (p400).

3. McLaughlin K, Jones A (2011) 'It's all changed': carers' experiences of caring for adults who have Down's syndrome and dementia. British Journal of Learning Disabilities 39: 57–63

Method: Qualitative

Data: Views and experiences

Country: UK

Outline

This study features qualitative interviews with 6 carers, paid and unpaid, working with people with Down's syndrome who have developed dementia. The study is of moderate quality (+) and has a good level of relevance to the question (++). The study used interviews and aimed to gather views and experiences about what information and support these carers needed as they dealt with the changes that came with dementia. The study produced thematic findings in relation to 6 carers. The study provides insight into how carer needs for information and support change around diagnosis.

Findings

Carers described information needs pre- and post-dementia diagnosis. The study organises its findings under thematic headings.

Pre-diagnosis

Information needs were at their highest before diagnosis, when carers had begun to notice changes in behaviour. The study found that carers did not necessarily realise the significance of the behavioural changes.

Carers did not seek information or advice because they did not realise the changes could be associated with dementia: ‘I didn’t say anything because again I thought that perhaps it’s me being a bit (pause) oh why is he doing that? But they noticed at the day centre … and they mentioned it to the community nurse and well she made an appointment to see the doctor’ (p60).

Diagnosis

Diagnosis led to new information needs about the implications of the diagnosis and the progress of the disease.

Some carers had questions about the different types of dementia. The study found that carers were aware of different symptoms in adults with dementia but they were not aware of the specific type of dementia that each adult had: ‘We have another service user who suffers from dementia and obviously everyone is an individual and it was totally different with him’ (p60).

Carers were happy to get a diagnosis but had questions about the progress of the disease: ‘I would like to know how long a Down’s syndrome could last with Alzheimer’s’ (p60).

Post-diagnosis

Post-diagnosis carers sought practical and emotional support from friends, family and professionals. ‘Yeah as I said I’m alright for support because I’ve got my relative next door but if I didn’t have her I probably would be glad of some support’ (p60).

Changing needs

Carers who became more involved with the care of the person with dementia had increased information needs. The study found that, initially, existing support was able to assist with changing behaviour due to dementia. Post-diagnosis, the increase in medical appointments meant more carer involvement. Carers needed more information and more support at this stage: ‘Extra professional and familial support may now be necessary as the adult with Down’s syndrome becomes increasingly affected by the dementia’ (p61).

Post-diagnosis, carers reported that their information needs lessened. Carers said that they had gathered all the information they needed about dementia symptoms and the progress of the disease. Carers believed that the disease would progress quickly and the person with dementia would need extra support. ‘I’m told that it’s going to get worse and when that happens like I said as much as I love him he’ll have to go into care’ (p61).

The study found that carers may lack information about support available to them. Carers did not know about respite and other services. Carers learnt of extra support through interactions with professionals, sometimes by chance: ‘The social worker has been very helpful he’s been good. He’s got respite for us’ (p61).

‘It was through the nurse that I had the chair. I was telling her how difficult it was when I was coming downstairs to the toilet with him … she said about getting a chair for the bedroom for him’ (p61).

The study surmises that information needs change with each stage of the onset and progress of dementia. Some carers amassed a lot of information at diagnosis and others sought new information as needs changed. Support needs increased, especially if services did not have capacity to help and the carers lacked support. Carers could become isolated and in financial difficulty if they could not work: ‘once my husband died I was scuppered’ (p61).

4. Tozer R, Atkin K (2015) ‘Recognized, valued and supported’? The experiences of adult siblings of people with autism plus learning disability. Journal of Applied Research in Intellectual Disabilities 28: 341–51

Method: Qualitative

Data: Views and experiences

Country: UK

Outline

This is a moderate (+) quality study, which explored relationships between adults over 25 years of age and their siblings who have autism and a learning disability. The aim of the study was to establish the extent of the siblings’ involvement in the lives and support of the brother or sister. The researchers conducted interviews with siblings, adults with a learning disability and relevant practitioners identified by the siblings. The findings from the practitioner interviews had little relevance to our review question so the data reviewed and presented to the Guideline Committee are mainly derived from the sibling interviews.

Findings

A total of 21 siblings agreed to participate in the study, 14 women and 7 men. They ranged in age from 25 to 67, and the ages of their sibling with a learning disability ranged from 24 to 65 years.

Approximately 1/3 of the siblings felt unfairly and negatively judged by professionals who didn’t seem to appreciate the difficulties of juggling life, work, family and time with the brother or sister with a learning disability. The amount of involvement they were able to have in their sibling’s life varied and whatever they were able to manage they wanted to be supported in this role by professionals.

One problem was that siblings were often excluded from discussions, which had started in the family home when they were young, so from the start they were never included in future planning. This wasn’t perceived as always being the fault of practitioners – some felt their parents had acted as gatekeepers.

Looking to the future, siblings felt they would be taking on more responsibilities but they would welcome support from practitioners to do this. Their experience was that practitioners weren’t sufficiently proactive in the sense of future planning discussions.

The authors conclude that findings seem to point to a need for training in social care organisations so that practitioners can work successfully with siblings of adults with learning disabilities. As a result practitioners should:

- recognise, value and support siblings in their role
- begin conversations with siblings earlier on in their lives
- provide information, a listening ear and practical help to siblings

Information and advice should include future care options and bereavement support for their brother or sister.

c) Views of practitioners – none specifically located (although some relevant data are reported in the above studies)

Economics

No cost-effectiveness studies were identified and no additional economic analysis was undertaken for this review question.

Evidence statements

The evidence statements listed in this section synthesise the key themes across included studies.

FCA1	There is a small amount of evidence that families of older people with learning disabilities are not given the support and information needed to take an active role in planning. The quality of the evidence is moderate. A UK study by Atkins and Loverseed (2012 +) found that some carers felt excluded from care planning and this was attributed to not being sufficiently well informed about the older person's health condition (p1). Another UK study by Tozer and Atkin (2015 +) found that siblings of older people with learning disabilities wanted to take on more responsibilities in the future and wanted support from professionals to do this. They felt that in general professionals were not proactive in involving them in future planning (p8).
FCA2	There is a small amount of evidence that information about dementia and adults with learning disabilities is particularly lacking, leaving families uninformed and unprepared. The quality of the evidence is moderate. A UK study by Atkins and Loverseed (2012 +) found that families had little information about dementia and how it would progress. They did not know where to look for reliable information and ended up using informal sources, which often led to further confusion (p1). Another UK study (McLaughlin and Jones 2011 +) reported that the need for information was greatest before the person had been diagnosed with dementia and was generally not available. Following diagnosis, families needed specific information about the disease and its likely progress and impact (p5).
FCA3	There is a small amount of evidence that support needs for families and carers of older people with learning disabilities and dementia are not being met. The quality of the evidence is moderate. The study by Atkins and Loverseed (2012 +) reported that some family carers were reluctant to ask for formal support because of past negative experiences with professionals and services (p1). The UK study by McLaughlin and Jones (2011 +) found that carers' support needs increased after the older person with a learning disability had been diagnosed with dementia, e.g. because of the increase in medical appointments. Families and carers needed to access respite services but did not know how (p5). The US study by Janicki et al. (2010 +) also found that carers had unmet needs from respite services (p4).
FCA4	There is a small amount of evidence that carers turn to their own families as their main source of support, not least because formal support may be lacking.

	The quality of the evidence is moderate. The US study by Janicki et al. (2010 +) found that parent carers intended to ask for help from their other children and their ability to care for the older person at home depended to a large extent on the availability of their family to share in the role (p4). The UK study by McLaughlin and Jones (2011 +) found that carers sought practical support from friends and family as well as professionals. The fact that they had friends and family nearby meant they could delay trying to access formal support (p5).
FCA5	There is a small amount of evidence that some family carers of older people with learning disabilities need specialist training, particularly in relation to additional conditions. The quality of the evidence is moderate. The study by Atkins and Loverseed (2012 +) found that carers wanted professional advice about how to communicate with the older person with a learning disability and this was particularly following a dementia diagnosis (p1). The study by Janicki et al. (2010 +) also found that family carers wanted training on specialist dementia care to help them provide the right support (p4).
FCA6	No evidence was found from studies published since 2005 about the effectiveness and cost-effectiveness of specific interventions or training programmes for families and carers of older people with learning disabilities.

Included studies for these review questions

Furniss KA, Loverseed A (2012) The views of people who care for adults with Down’s syndrome and dementia: a service evaluation. British Journal of Learning Disabilities 40: 318–27

Janicki MP, Zendell A, DeHaven K (2010) Coping with dementia and older families of adults with Down syndrome. Dementia 9: 391–407

McLaughlin K, Jones A (2011) ‘It’s all changed’: carers’ experiences of caring for adults who have Down’s syndrome and dementia. British Journal of Learning Disabilities 39: 57–63

Tozer R, Atkin K (2015) ‘Recognized, valued and supported’? The experiences of adult siblings of people with autism plus learning disability. Journal of Applied Research in Intellectual Disabilities 28: 341–51

3.4 Improving access and referral to health, social care and housing support services for older people with learning disabilities

Introduction to the review questions

Review question 5, comprised of parts a, b and c, is reported in this sub-section. Part a sought data about the acceptability, effectiveness and cost-effectiveness of interventions or approaches to improve access and referral to health, social care and housing support for older people with learning disabilities. Part b was designed to locate the self-reported views and experiences of older people with learning disabilities and their families and supporters about access and referral to health, social care and housing support services, including what works and what does not work well. Finally, part c sought the views and experiences of people delivering, organising and commissioning social care, health and housing services about access and referral to care and support for older people with learning disabilities. This includes views on what works and what does not work well in ensuring access and referral.

Review questions

5a. What is the acceptability, effectiveness and cost-effectiveness of interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities?

5b. What are the views and experiences of older people with learning disabilities and their carers about interventions or approaches to improve access and referral to health, social care and housing support services?

5c. What are the views and experiences of health, social care and other practitioners about interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities?

Summary of the review protocol

The protocol sought to identify studies that would:

- Identify the effectiveness and cost-effectiveness of interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities.
- Identify emerging models and approaches to improving access and referral to health, social care and housing support services for older people with learning disabilities and associated outcomes.
- Describe the self-reported views and experiences of older people with learning disabilities, their families and supporters about access and referral to health, social care and housing support services. This included what works and what does not work well.
- Describe the views and experiences of people delivering, organising and commissioning social care, health and housing services about access and referral to care and support for older people with learning disabilities. Includes views on what works and what does not work well in ensuring access and referral.

Population

Older people with learning disabilities and care and support needs, their families, supporters and carers.

Social care practitioners (providers, workers, managers, social workers), housing practitioners and health and social care commissioners involved in delivering care and support at home to older people with learning disabilities.

Intervention

Care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities.

Setting

People’s own homes, family homes and temporary accommodation such as hostels and respite arrangements; supported living, residential and nursing care homes (including hospices). Primary healthcare, outpatients and community hospitals.

Outcomes

Person-focused outcomes (independence, choice and control over daily life; capability to achieve desired person-centred outcomes; user and carer satisfaction;

continuity of care; health and social care-related quality of life, including carer quality of life; years of life saved) and service outcomes (use of health and social care services and housing support; need for support from health and social care practitioners and carers; delayed transfers of care from hospital; hospital admissions and readmissions; admission to care homes; length of stay in hospital and care homes). See 1.6 in the scope.

Study design

The study designs relevant to the ‘effectiveness and cost-effectiveness’ part of this question included: systematic reviews of studies of interventions to improve access and referral to care and support for older people with learning disabilities; randomised controlled trials (RCTs) of interventions to improve access and referral to care and support for older people with learning disabilities; economic evaluations; quantitative and qualitative evaluations of different approaches; observational and descriptive studies of process; cohort studies, case control, before and after studies and mixed methods studies.

The study designs relevant to the ‘views and experiences’ parts of this question included: systematic reviews of qualitative studies on this topic; qualitative studies of user, carer and practitioner views of interventions to improve access and referral to care and support for older people with learning disabilities; qualitative components of effectiveness and mixed methods studies; observational and cross-sectional survey studies of user or carer experience.

See Appendix A for full protocols.

How the literature was searched

One single search was conducted for all but 1 of the review questions (end of life care). Electronic databases in the research fields of health (including mental health), social care, social science and economics were searched using a range of controlled indexing and free-text search terms. Additional searches of websites of relevant organisations, and trials registries were undertaken to capture literature that may have been missed from the database searches. The search was based upon 2 concepts: a) older people, ageing and future planning, or aged care services; and b) intellectual or learning disabilities.

A wide range of search terms were used to find these 2 concepts. The search terms were developed from various methods. This included finding 52 items that related to the topic, and discovering relevant search terms.

See Appendix A for full details of the search.

How studies were selected

Search outputs (title and abstract only) were stored in EPPI Reviewer 4 – a software program developed for systematic review of large search outputs. Coding tools were applied and all papers were screened on title and abstract. Formal exclusion criteria were developed and applied to each item in the search output, as follows:

- Language (must be in English).
- Population (For question 5b, must be about older people with learning disabilities, their families or supporters. Note that in line with the scope, a specific age limit will not be used to define older people so a flexible and pragmatic approach to screening on the target population will be taken. For question 5c, must be about social care practitioners involved in delivering care and support at home to older people with learning disabilities.)
- Intervention (must be about approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities).
- Setting (Must be people's own homes, family homes and temporary accommodation such as hostels and respite arrangements; supported living, residential and nursing care homes, including hospices. Primary healthcare, outpatients and community hospitals.)
- Country (must be UK or other OECD).
- Date (must not be published before 2005).
- Type of evidence (must be research).

Title and abstract of all research outputs were screened against these exclusion criteria. Those included at this stage were marked for relevance to specific review questions and retrieved as full texts.

Full texts were again reviewed for relevance and research design. A list of studies excluded on full text can be found in Appendix A, organised by exclusion criteria.

If still included, critical appraisal (against NICE tools) and data extraction (against a coding set developed to reflect the review questions) was carried out. The coding was all conducted within EPPI Reviewer 4, and formed the basis of the analysis and evidence tables. All processes were quality assured by double coding of queries, and of a random sample of 10%.

See Appendix B for full critical appraisal and findings tables.

Overview of evidence

In our initial screen (on title and abstract) we found 30 studies which appeared relevant to review question 5. We retrieved and then reviewed full texts and included a total of 7 papers. The views and experiences of older people with learning disabilities and their families were represented (n=3), as well as views and experiences of practitioners (n=4). The evidence was focused on barriers to access. No evidence was found on effectiveness or cost-effectiveness of interventions to improve access and referral. There were gaps in evidence about access to housing support services, which led to the Guideline Committee seeking expert testimony on this subject.

Narrative summary of the evidence

In this section, a narrative summary of each included study is provided, followed by a synthesis of the evidence, according to the key outcomes, themes or sub-groups in the form of evidence statements (p119). The approach to synthesising evidence was informed by the PICO within the review protocol.

The following studies provide data about access to health, social care and housing support for older people with learning disabilities.

a) Acceptability and effectiveness – no data located

b) Views of older people with learning disabilities/their carers and supporters

1. Mac Giolla Phadraig C, Burke E, McCallion P et al. (2014) Dental attendance among older adults with intellectual disabilities in Ireland. Special Care in

Dentistry: Official Publication of the American Association of Hospital Dentists, the Academy of Dentistry for the Handicapped, and the American Society for Geriatric Dentistry 34: 265–72

Method: Qualitative

Data: Views and experiences

Country: Republic of Ireland

Outline

This is a moderate quality (+) mixed methods study to investigate dental attendance patterns among older people with learning disabilities and the reasons for those patterns. The study has good relevance (++) to our review question since it explores issues around access to dentists and dental appointments for our guideline population. The study was conducted in the Republic of Ireland using data drawn from the first wave of the Irish Longitudinal Study on Ageing (IDS - TILDA). Data from 727 responses regarding dental attendance patterns were included and all of those people were invited to participate in the qualitative phase of data collection which included a pre-interview questionnaire and face-to-face interviews.

Findings

The study found that age and type of residence were associated with frequency of dental attendance (Pearson's chi-square test, $p<0.01$); the proportion of irregular attenders increased with age and the proportion of regular attenders was lowest among people living independently. The specific explanation given for the connection with residential setting was that dentists generally visit selected residential services annually and people outside the residential system aren't so easily targeted.

The connection with age (people attend the dentist less frequently the older they get) is a trend reflected in the general population and suggests that the proportion of people failing to access dental services will increase as the learning disabled population ages.

Neither gender nor level of disability were associated with frequency of attendance.

From the qualitative data the reasons given for being an irregular attender included the following.

Lack of perceived need

There is a misperception about the need for dental care – even if someone has no teeth, they should still attend dental checks where, for example, the early signs of mouth cancers can be identified. A total of 64% of irregular attenders felt that because they had no teeth, they need not see the dentist, ‘I have no teeth and I have no problems with my mouth’ (p268).

Ability and personal choice

This included mobility problems preventing a person physically accessing the dentist. Also fear: when people are scared of the dentist they won’t access it, ‘I am terrified of a dentist – I had a terrible experience when I was a child ...’ (p268).

Access and availability

Difficulties with accessing dental services were cited by 4% (6/153 responses available for analysis) of irregular attenders. Participants identified barriers arising from interactions between dental and disability services: ‘Currently there is no dental service available within the [disability] service, however, when the [disability] service moves into the community ... which is in operation at the moment ... there will be a [dental] service available’ (p268). A lack of general anaesthetic facilities also restricted access. One person used to have her teeth cleaned under general anaesthetic but due to funding cuts this is no longer available so she hasn’t had them cleaned for 3 years. This suggested that such barriers may underrepresent choice as the main reason for nonattendance among a minority of older people with intellectual disabilities.

It therefore appears that access to dental care needs to be improved for older people with learning disabilities who are living independently (including with families). However, note that according to the findings of this study ‘access’ is affected by a range of things including personal choice and awareness of the importance of dental care.

2. Swaine JG, Dababnah S, Parish SL et al. (2013) Family caregivers’ perspectives on barriers and facilitators of cervical and breast cancer

screening for women with intellectual disability. Intellectual and Developmental Disabilities 51: 62–73

Methods: Qualitative

Data: Views and experiences

Country: USA

Outline

This is qualitative study from the USA was well conducted (++) and its findings could be generalised well to our setting (++). They interviewed 32 female familial caregivers living at home with older women with intellectual disabilities. They aimed to investigate what these carers believed helped or hindered access to several types of female health check, as well as how adequate they felt services were and how much they knew about health screening themselves. The interviews were conducted by phone, asking some set questions about particular topics but allowing plenty of room for the caregivers to elaborate in their answers. Originally they had hoped to interview 50 caregivers, but 18 of them didn't complete a phone call because they could not be contacted, or because they or their relatives didn't agree to participation.

Findings

What helps or hinders access to breast exams?

Most women (83%) had previously had a breast exam. In many cases the experience had been comfortable and the caregivers gave 3 reasons. First the doctor or caregiver explained the procedure, secondly the doctor's gender was female and finally the woman with intellectual disability was familiar with the doctor. It was important they could accompany them during the exam, and several stated they would not allow an exam outside of their presence.

One common reason for non-attendance was the caregiver's belief that the exams were unnecessary.

What helps or hinders access to mammograms?

Eight of the women with learning disabilities were aged over 40 (ranged from 20 to 69 years) at the time and 6 had previously had a mammogram. Most had been comfortable with the procedure, primarily because the relative had prepared them. However, 2 had been uncomfortable because the procedure was unexpected and they believed it was painful.

What helps or hinders access to pap/pelvic exams?

About 3/4 of participants had received pap/pelvic exams, but only half of those had had an exam in the past year. The most common reason for not getting an exam was that the person was not sexually active. Several didn't feel it was necessary and stated they hadn't been recommended to by their doctor. Forewarning, and the caregivers comforting presence, had enabled access. In 2 cases the women had also had to receive anti-anxiety medication.

How did caregivers feel about their disabled relative's healthcare?

Most family caregivers (87%) reported their family member with learning disabilities received adequate healthcare. The most common reason given was they that themselves championed them and pushed for proper care. In return, medical professionals worked to make sure appointments were convenient and available to them. It also helped when the clinical staff were competent with facilitating learning disabilities.

3. Wark S, Canon-Vanry M, Ryan P et al. (2015) Ageing-related experiences of adults with learning disability resident in rural areas: one Australian perspective. British Journal of Learning Disabilities 43: 293–301

Method: Qualitative

Data: Views and experiences

Country: Australia

Outline

This is a good quality (++) pilot study, which is moderately relevant (+) to our review question. The study was designed to explore the ageing-related experiences of people with learning disabilities in rural Australia, particularly in relation to accessing services. Interviews with older people with learning disabilities and their carers investigated what helps and what hinders in accessing support. The data reported in the study are a subset of information gained from a larger study across 2 states of Australia: New South Wales and Queensland. A total of 34 interviews were conducted (17 older people with learning disabilities and 17 nominated carers). The age range of the older adults was 54–79 years. Interviews were transcribed verbatim and analysed by the whole team in a 2-stage process involving the identification of themes and development and use of a coding structure.

Findings

Not all of the thematic areas were relevant to our review question. The ones providing the most relevant data are described here.

1. Access to health services

Access to healthcare – especially specialist services – was deemed to be a key aspect of having a ‘good life’. Participants were happy with the support from their local doctor. ‘He knows Dennis really well. He’s got a good rapport with Dennis. And he takes on board whatever the staff are telling him as well’ (support worker, p297).

The smaller population in rural areas was sometimes seen as a benefit in terms of being able to access local doctors, but on the other hand some people reported long waits for appointments and that the only option would be to go to the emergency department (and wait for hours). However, the big issue seems to have been accessing specialist services. As the person with the learning disability ages they need to see a gerontologist and the chances of this are low since ‘We can’t even get a GP to some age care facilities it is so hard’ (carer for Stephen, age 79, own home) (p298).

Distance (‘the tyranny of distance’) seems to be the biggest barrier in rural Australia. While there were allied health practitioners with knowledge or specific interests in learning disability and specialist services nominally available, the individuals were required to travel often considerable distances to attend these appointments (p298). Ken – aged 57, living in a group home – had to travel a 700km round trip to see his health specialist. Also Graeme – aged 54, living in own home – had to get his prescription medication from the next town, 100km away.

2. Limited choices and limited options

Carers identified a clear lack of options for adults ageing with a learning disability. The issue is twofold: there is a lack of services and a lack of choice in provision of services. Even if there are services, there’s only 1, so the person has no choice about which to use. ‘That’s basically only one option for them at the moment, especially in [this town] and even the rural areas. They won’t have anywhere for those people to go, the only option is nursing homes and I don’t believe a nursing home is a place for them’ (Brenda, support worker for Dennis [age 55, supported unit]) (p298).

If the person isn’t happy with the services of a given place as they grow older (for example, a supported unit) the only alternative was a mainstream residential aged care provider. The authors conclude that the right of the individual to make meaningful choices in their life is irrelevant as a philosophy if there are no options from which to select.

c) Views of practitioners

4. Benbow SM, Kingston P, Bhaumik S (2011) The interface between learning disability and old age psychiatry: two specialties travelling alone or travelling together? Mental Health Review Journal 16: 25–35

Methods: Survey

Data: Views and experiences

Country: UK

Outline

This study by the Royal College of Psychiatrists in the UK was judged to be of moderate quality (+) and moderately relevant to the review question (+).

The authors wanted to know what services were needed for older people with learning disabilities and how they should best be accessed. They sent a postal survey to 942 members of the College – registered in either old age psychiatry or in learning disabilities, asking them about how these services currently worked. They received 444 responses (47%), mostly from consultants – 66% of whom worked in old age psychiatry and the remainder worked in learning disabilities. Questions centred on what services existed; what positive experiences they had had dealing with these groups of people; what gaps existed in the current service provision; and whether there were any particular problems in accessing or providing services.

Findings

The current state of services

The service models that currently exist in the UK are highly variable. Some services have well established protocols that outline how responsibilities are designated for dealing with older people with learning disabilities. Patients who access older people's services can access learning disability services and vice versa. However, other areas have very little clarity on which service should meet particular needs.

Practitioners in each service often had problems when they and their patients tried to establish contact to access the other service. Often the other service was on a different site in the same area. Additionally, learning disability practitioners commented that old age services don’t always take people with learning disabilities.

When it comes to learning disabilities and dementia many practitioners felt there is a need for specific services in their areas but they don’t currently exist to be accessed.

5. Coyle CE, Putman M, Kramer J et al. (2016) The role of aging and disability resource centers in serving adults aging with intellectual disabilities and their families: findings from seven states. Journal of Aging and Social Policy 28: 1–14

Method: Qualitative

Data: Views and experiences

Country: USA

Outline

This is a moderate quality (+) views study conducted in the USA, which was judged to have moderate relevance (+) to our review question. The objective of the study was to develop an understanding of how aging and disability resource centres (ADRCs) issue resources and support to older adults with learning disabilities and their families. The researchers conducted in-depth qualitative interviews with 7 (out of a potential 8) state ADRC coordinators and 14 (out of a potential 21) local ADRC staff, giving an overall sample of 21 practitioners. All interviews were audio recorded and transcribed verbatim and then a constant comparative approach (involving 2 researchers) was used to generate primary and secondary themes from the data.

Findings

Emergent themes were summarised into 3 major findings about access to information and referrals for older people with learning disabilities.

1. Staff who reported that there is no explicit focus on adults ageing with learning disabilities and their families in the ADRCs' work

Across all states ADRC staff were aware of adults with learning disabilities as a population, however, they were not considered a specific focus population for their ADRC. Staff views fell into 3 main perspectives about how older people with learning disabilities fit into the work of ADRCs:

- adults with learning disabilities and their families do not have any special needs that would separate them from the broader service population or require a particular approach
- adults with learning disabilities will be an important group to target in future but they're not being addressed in the current work of the ADRCs, 'we're always saying that ... this is an issue – as people are living longer and parents pass away, but we haven't necessarily carved them out yet' (p5)
- attempts are being made to unite services for older people with services for adults with learning disabilities so that the needs of the older learning disability population can be addressed – and these efforts will continue into the future.

2. Staff who reported unique challenges in providing information and referral services to older people with learning disabilities, which result in complexities or gaps in services for this section of the population

ADRC staff identified 3 common challenges in providing adequate support to older people with learning disabilities, as follows.

- Adults with learning disabilities (or their families) often contact the ADRC in times of crisis because they are not already connected with formal services. Staff are therefore starting at the beginning in terms of determining eligibility and getting access to support for the person and this is more demanding in terms of staff time and resources. In crisis situations it is also often the case that the ageing parent needs immediate support.
- ADRCs do not necessarily resonate with the older learning disabled population (or their families) – they don't necessarily identify as 'disabled' so it wouldn't occur to them that the ADRC could provide them with support.

- The provision of information and referral services to older people with learning disabilities is challenging to a system that is set up for providing support to older people (but not those with learning disabilities). The divide between older people's and learning disability services made it unlikely these problems could be addressed.

Another difference in the need for service delivery that makes it hard for ADRC staff to provide information and referral is that families are often the first point of contact for older people with learning disabilities. Coordinating between families, the older person with learning disabilities and referral agencies makes it hard to streamline services across ageing and disability services;

'We place a very high priority on getting the primary guidance [from] the person with the disability. [For example] we cannot provide advocacy related to benefits ... unless we are talking directly with the person who has the disability or their legal representative. And so if you have a sibling or a friend who isn't in that position of having the legal representation ... calling ... we can't just dive straight into solving the problem. That could definitely be a barrier' (p8).

Two other problems in services were highlighted:

- eligibility requirements based on age mean that younger adults with learning disabilities (experiencing accelerated ageing) aren't eligible for the same information and direct services available to the general ageing population

- a lack of services to meet the needs of the growing general population, let alone the growing population of adults with learning disabilities who are ageing.

3. Staff who said that the needs of adults ageing with learning disabilities for 'long-term support and services' (LTSS) are perceived as parallel to those of older adults without learning disabilities, but appropriate tailoring or delivery models to address those needs are lacking

Staff reported that LTSS services aren't designed to include the older people with learning disabilities population and, in some cases, where the service could be appropriate it cannot be accessed because of eligibility criteria (sometimes tied to funding).

One exception was housing and home adaptations where it's less challenging to meet the needs of older people with learning disabilities with universal services – this includes finding suitable housing and adapting current housing.

6. Dodd P, Guerin S, Mulvany F et al. (2009) Assessment and characteristics of older adults with intellectual disabilities who are not accessing specialist intellectual disability services. Journal of Applied Research in Intellectual Disabilities 22: 87–95

Method: Qualitative

Data: Views and experiences

Country: Republic of Ireland

Outline

This qualitative study conducted in the Republic of Ireland is of moderate quality (+) with a moderate level of relevance to the review question (+). The study is made up of 2 sections. Only the second part is relevant to this review question. The study aims to analyse how key workers responded to a questionnaire on the assessment and support practices of service providers for older people with learning disabilities who have been identified as being outside services (part 1 of the study aimed to identify a representative sample of older individuals with learning disabilities who were outside of services). The questionnaire was responded to by key workers in relation to 43 cases. The study presents a mix of rich data from the questionnaire and some statistical data about how people who failed to access services were responded to by key workers. There was no follow up.

Findings

Contact with individuals with learning disabilities

The mean time since the key workers' contact with the target individual was 5.3 months. There were 4 cases where no information was given, 10 cases where there was no contact with the individual and 6 cases where the last contact was 12 months or more.

Contact with families supporting a person with learning disabilities

The mean time since the key worker had any contact with the family was 5.2 months. In 11 cases there was no contact with the family and in 7 cases the last contact was 12 months or more before the time of data collection.

Data from key workers about the reasons for ceasing contact with an individual

Reason for ceasing contact: individual had no current service needs:

- 60% agreed
- 28% disagreed
- 12% missing data or comments that no opinion could be given.

Key workers gave various accounts of the context of ‘a lack of service need’. Key workers said they ceased contact with individuals when they felt that the family provided satisfactory care: ‘His sister involves him in the working of the farm as well as going to social activities with family members. The person appears very happy with the current situation’ (p92).

‘Supportive family. Four adult sisters care for him and they say that between them they will always look after him’ (p92).

Some key workers had ceased contact because the family said that there was no need for specialised services before an assessment had been carried out. Key workers that disagreed with the decision to cease contact usually did so on the basis that they thought the individual may benefit from social activity.

In some cases key workers reported that the individual themselves said that they did not want help from services, but in most cases key workers said that said that the family felt that the individual was happy at home, happy with current service use or that the family were not offered services or appropriate services were not available. The data reflected a variety of views, as follows.

‘The cultural influences of being Jamaican [mother’s ethnicity] is possibly a factor here. Both mother and son enjoy a good relationship and have established a way of coping that excludes services’ (p92).

‘Family are elderly. Have coped without intervention for years. Feel that they can continue to manage independently. Lack of knowledge of services has caused apprehension. Fear of split of family unit’ (p92).

‘Mother considers her son as not being appropriate for a day service and thinks that he wouldn’t be happy in a service’ (p.92).

Eleven key workers said that in most cases families were not encouraged to engage in services (25.6%). Others said they encouraged families to engage and would inform them if more suitable services were created.

7. McIlfatrick S, Taggart L, Truesdale-Kennedy M (2011) Supporting women with intellectual disabilities to access breast cancer screening: a healthcare professional perspective. European Journal of Cancer Care 20: 412–20

Method: Qualitative

Data: Views and experiences

Country: UK (Northern Ireland)

Outline

This is a moderate quality (++) UK study with a good level of relevance to our question (++). The study aimed to gather healthcare professionals’ perspectives on the accessibility of breast cancer screening for women with learning disabilities. The objectives included exploring healthcare professionals’:

- knowledge and awareness of breast cancer and breast screening among women with learning disabilities
- roles and experiences of supporting women with intellectual disability to access breast screening services
- perceptions of the barriers and solutions as to why women with intellectual disabilities access breast screening services or not.

The study used a sample of 18 professionals, 9 from primary care and 9 from a breast cancer screening unit. Researchers gathered data via telephone interviews and a focus group. Results are thematically organised and the findings contain a good deal of rich data. The study offers information about the barriers and facilitators to women's access to breast screening. The population is not explicitly older people, but the review team took a pragmatic approach, given that breast screening is usually offered from the age of 50. There was no follow up.

Findings

Knowledge and awareness of breast cancer and breast screening
The importance of women with intellectual difficulties being screened for breast cancer – the reason for this was for early intervention and prevention:

practitioners were well informed about the particular risks associated with breast cancer for women with learning disabilities. Practitioners identified risks associated with limited cognitive function, ability to self-examine, lack of knowledge of breast cancer, literacy skills and difficulty dealing with correspondence and attending appointments.

Other risks identified in the interviews that could affect attendance were poor diet, medical history and hormone medications, and not having children.

Practitioner roles in supporting women with intellectual disability in accessing screening services: health professionals tried to encourage women with learning disabilities to attend breast screening.

Health Promotion: GPs used routine visits to promote breast screening, and liaison with family or community disability teams.

Professionals who worked in screening units had a role in explaining the procedure to people and then offering health advice before and after, also involving carers. If there was a diagnosis, they referred them on to other services.

Barriers to women with intellectual disabilities accessing breast screening services
The barriers associated with women with intellectual disabilities were linked to their cognitive abilities, communication issues and issues with understanding. Some women may also have limited mobility and poor physical health. The issue of consent was also a concern – that is, if women were felt to be unable to consent to

the procedure and possible treatment. Other patients may say that they do not want the screening to be done.

Barriers attributed to carers

It was felt that carers were helpful in supporting women in screening and so those without support were at a disadvantage. Another view was that carer attitudes can be a barrier. For example, when carers made the decision not to do the screening: ‘The decision could be taken for them [women with learning disabilities] by carers and relatives [who] may feel that it’s not what they need, that it might cause them distress. So the decision may not necessarily be taken by the patient themselves’ (p416).

Practical barriers

Factors like the time of appointments and transport links were cited.

Barriers attributed to healthcare professionals

Barriers included attitudes, awareness levels, experience of learning disability and training. The study states that there may be a need for more training. Some participants said that the health practitioner had a lack of awareness of older people with learning disabilities and did not consider how their needs may be a barrier to breast screening.

The focus groups described GPs as gatekeepers for women to access breast screening.

Solutions to women with intellectual disabilities accessing breast screening

The groups discussed what was needed to assist women to access breast screening:

- awareness among practitioners around the needs of older women with learning disabilities
- promotion of interdisciplinary working
- promotion of integrated working
- links with GPs.

Economics

No cost-effectiveness studies were identified and no additional economic analysis was undertaken for this review question.

Evidence statements

The evidence statements listed in this section synthesise the key themes across included studies.

AR1	There is a small amount of evidence that older people with learning disabilities who live independently have poor access to dental care. The quality of the evidence is moderate. Mac Giolla Phadraig et al. (2014 +) found that the proportion of regular dentist attenders was lowest among people living independently and this is perhaps owing to the fact that dentists generally visit selected residential services on an annual basis (p1).
AR2	There is some evidence that older people with learning disabilities can lack understanding and awareness about the importance of health interventions and this can limit their access to services. The quality of this evidence is mainly moderate. Mac Giolla Phadraig et al. (2014 +) found that irregular dentist attenders made a choice not to access this service – sometimes out of fear or because they were unaware of the importance of dental checks (p1). Dodd et al. (2009 +) found that 1 of the reasons older adults were not accessing specialist learning disability services was that individuals themselves did not want this support (p12). McIlfratick et al. (2011 ++) identified a lack of understanding about breast examinations and breast cancer among women with learning disabilities, which acted as a barrier to accessing breast screening services (p15).
AR3	There is a moderate amount of evidence that older people with learning disabilities have limited access to support because of a lack of services designed specifically to address their needs and preferences. The quality of the evidence is mostly moderate. Wark et al. (2015 ++) found that in rural Australia, older people with learning disabilities had to travel very long distances from home in order to access specialist health services. In addition, where learning disability services were available locally, access was limited by having few, if any, options (p5). Benbow et al. (2011 +) reported that learning disability practitioners said psychiatry services for older people in the UK specifically exclude people with learning disabilities (p8). The US study by Coyle (2016 +) reported clear difficulties from a practitioner perspective around being able to provide resources and support to older people with learning disabilities. As a result staff admitted to not addressing the needs of the specific population in the provision of services although it was something they recognised they ought to do in future (p9). Finally, a study conducted in Ireland (Dodd et al. 2009 +) found that 1 of the reasons older adults with learning disabilities did not access specialist learning disability services was that their families judged that they were not appropriate to meet the person's needs (p12).
AR4	There is some evidence that a lack of awareness and understanding among practitioners about supporting older people with learning disabilities has the effect of reducing access to support. The quality of the evidence is good. Research in rural Australia (Wark et al. 2015 ++) showed that having a GP who knows the older person with a learning disability, understands their needs and can communicate well was a key aspect of providing access to healthcare and

	ensuring a ‘good life’ (p5). A Northern Ireland study (McIlfratick et al. 2011 ++) found that health professionals have an important role in explaining breast examinations to women with learning disabilities and that this promotes access by putting them at ease and encouraging them to attend appointments (p15). Similarly in a US study (Swaine et al. 2013. ++) family carers believed that having a doctor who is competent with facilitating learning disabilities and explains a medical procedure in advance helped women with learning disabilities to access breast exams (p3).
AR5	There is a moderate amount of evidence that family carers have an important influence over whether older people with learning disabilities access support. The quality of the evidence is moderate to good. In the study by Dodd et al. (2009 +) key workers said that 1 of the reasons older people with learning disabilities do not access specialist services is that families opt to support the person themselves and feel that formal services are therefore not necessary (p12). A US study by Coyle et al. (2016 +) reported that it can sometimes be problematic if families telephone the resource centre seeking financial or benefits advice for the person with learning disabilities unless they are established as the legal representative (p9). Practitioners in the McIlfratick et al. study (2011 ++) said that carers can be helpful in supporting women with learning disabilities to access breast cancer screening. On the other hand, they can act as a barrier to access if they do not believe screening to be something the person needs or if they think it will cause too much distress (p15). Finally, in the study by Swaine et al. (2013 ++) carers said the reason the older person with learning disabilities had accessed good quality health care was that they had themselves acted as the person’s champion (p3).
AR6	There is a small amount of evidence that practical difficulties associated with health appointments can act as a barrier to older people with learning disabilities accessing support. The quality of the evidence is good. In McIlfratick et al. (2011 ++) health practitioners said that women with learning disabilities could find it difficult to access breast cancer screening because they have difficulties dealing with correspondence and attending appointments. This underlines evidence already reviewed for questions 1 and 2 about difficulties in attending screening and assessments (p15). The US study by Swaine et al. (++) also chimed with this when family caregivers said that convenient appointments for them as carers helped in ensuring older people with learning disabilities could access breast cancer screening (p3).
AR7	No evidence was found from studies published since 2005 about the effectiveness of interventions to improve access to health, social care or housing services for older people with learning disabilities.
AR8	No evidence was found from studies published since 2005 about views and experiences connected with access to housing support services for older people with learning disabilities. Four studies explored people’s views about access to health services for older people with learning disabilities (Mac Giolla Phadraig et al. (2014 +), Swaine et al. (2013 ++), Benbow et al. (2011 +), McIlfratick et al. (2011 ++). Three studies reported people’s views about access to care and support more broadly (Dodd et al. 2009 +; Wark et al. 2015 ++; Coyle et al. 2016 +).

Included studies for these review questions

Benbow SM, Kingston P, Bhaumik S (2011) The interface between learning disability and old age psychiatry: two specialties travelling alone or travelling together? Mental Health Review Journal 16: 25–35

Coyle CE, Putman M, Kramer J et al. (2016) The role of aging and disability resource centers in serving adults aging with intellectual disabilities and their families: findings from seven states. Journal of Aging and Social Policy 28: 1–14

Dodd P, Guerin S, Mulvany F et al. (2009) Assessment and characteristics of older adults with intellectual disabilities who are not accessing specialist intellectual disability services. Journal of Applied Research in Intellectual Disabilities 22: 87–95

Mac Giolla Phadraig C, Burke E, McCallion P et al. (2014) Dental attendance among older adults with intellectual disabilities in Ireland. Special Care in Dentistry: Official Publication of the American Association of Hospital Dentists, the Academy of Dentistry for the Handicapped, and the American Society for Geriatric Dentistry 34: 265–72

McIlfatrick S, Taggart L, Truesdale-Kennedy M (2011) Supporting women with intellectual disabilities to access breast cancer screening: a healthcare professional perspective. European Journal of Cancer Care 20: 412–20

Swaine JG, Dababnah S, Parish SL et al. (2013) Family caregivers’ perspectives on barriers and facilitators of cervical and breast cancer screening for women with intellectual disability. Intellectual and Developmental Disabilities 51: 62–73

Wark S, Canon-Vanry M, Ryan P et al. (2015) Ageing-related experiences of adults with learning disability resident in rural areas: one Australian perspective. British Journal of Learning Disabilities 43: 293–301

3.5 Care planning and support for older people with learning disabilities to access volunteering, employment and adult learning, social and leisure activities, transport and

technology and maintain relationships with family, friends and within their local community

Introduction to the review questions

Review question 6, comprised of parts a, b and c, is reported in this sub-section. Part a sought data about the acceptability, effectiveness and cost-effectiveness of care planning and support for older people with learning disabilities to maintain relationships with family, friends and local communities and improve access to volunteering, employment and adult learning, social and leisure activities, transport and technology. Part b was designed to locate the self-reported views and experiences of older people with learning disabilities, their families, carers and advocates about care planning and support to maintain relationships with family, friends and local communities and improve access to volunteering, employment and adult learning, social and leisure activities, transport and technology. Finally, part c sought the views and experiences of people delivering, organising and commissioning social care, health and other services about care planning and support for older people with learning disabilities to maintain relationships with family, friends and local communities and improve access to volunteering, employment and adult learning, social and leisure activities, transport and technology. This includes views on what works and what does not work well.

Review questions

6a. What is the acceptability, effectiveness and cost-effectiveness of care planning and support for older people with learning disabilities to access volunteering, employment and adult learning, social and leisure activities, transport and technology and maintain relationships with family, friends and within their local community?

6b. What are the views and experiences of older people and their carers in relation to support for developing and maintaining relationships with family, friends and the local community?

6c. What are the views and experiences of health, social care and other practitioners about support for older people with learning disabilities to develop and maintain relationships with family, friends and the local community?

Summary of the review protocol

The protocol sought to identify studies that would:

- Identify the acceptability, effectiveness and cost-effectiveness of care planning and support for older people with learning disabilities to maintain relationships with family, friends and local communities and improve access to volunteering, employment and adult learning, social and leisure activities, transport and technology.
- Identify emerging models and approaches to maintaining relationships with family, friends and local communities and improving access to volunteering, employment and adult learning, social and leisure activities, transport and technology. Also, to identify outcomes associated with these emerging models.
- Describe the self-reported views and experiences of older people with learning disabilities, their families, carers and advocates about care planning and support to maintain relationships with family, friends and local communities and improve access to volunteering, employment and adult learning, social and leisure activities, transport and technology, including what works and what does not work well.
- Describe the views and experiences of people delivering, organising and commissioning social care, health and other services about care planning and support for older people with learning disabilities to maintain relationships with family, friends and local communities and improve access to volunteering, employment and adult learning, social and leisure activities, transport and technology. Includes views on what works and what does not work well.

Population

Older people with learning disabilities and care and support needs, their families, carers and advocates.

Social care practitioners (providers, workers, managers, social workers), housing practitioners and health and social care commissioners involved in delivering care and support at home to older people with learning disabilities.

Intervention

Care planning and support for older people with learning disabilities to maintain relationships with family, friends and local communities and improve access to volunteering, employment and adult learning, social and leisure activities, transport and technology.

Setting

People's own homes, family homes and temporary accommodation such as hostels and respite arrangements; supported living, residential and nursing care homes (including hospices). Primary healthcare, outpatients and community hospitals.

Outcomes

Person-focused outcomes (independence, choice and control over daily life; capability to achieve desired person-centred outcomes; user and carer satisfaction; continuity of care; health and social care-related quality of life, including carer quality of life; years of life saved) and service outcomes (use of health and social care services and housing support; need for support from health and social care practitioners and carers; delayed transfers of care from hospital; hospital admissions and readmissions; admission to care homes; length of stay in hospital and care homes). See 1.6 in the scope.

Study design

The study designs which were prioritised for the 'effectiveness and cost-effectiveness' question included: systematic reviews of studies of different models of discharge assessment and care planning; randomised controlled trials (RCTs) of different approaches to discharge assessment and care planning; economic evaluations; quantitative and qualitative evaluations of different approaches; observational and descriptive studies of process; cohort studies, case control and before and after studies; mixed methods studies.

The study designs which were prioritised for the 'views and experiences' questions included: systematic reviews of qualitative studies on this topic; qualitative studies of user and carer views of social and integrated care; qualitative components of effectiveness, mixed methods studies and observational and cross-sectional survey studies of user experience.

See Appendix A for full protocols.

How the literature was searched

One single search was conducted for all but 1 of the review questions (RQ 8: End of life care). Electronic databases in the research fields of health (including mental health), social care, social science and economics were searched using a range of controlled indexing and free-text search terms. Additional searches of websites of relevant organisations, and trials registries were undertaken to capture literature that may have been missed from the database searches. The search was based upon 2 concepts: a) older people, ageing and future planning, or aged care services; and b) intellectual or learning disabilities.

A wide range of search terms are used to find these 2 concepts. The search terms were developed from various methods. This included finding 52 items that related to the topic, and discovering relevant search terms.

See Appendix A for full details of the search.

How studies were selected

Search outputs (title and abstract only) were stored in EPPI Reviewer 4 – a software program developed for systematic review of large search outputs. Coding tools were applied and all papers were screened on title and abstract. Formal exclusion criteria were developed and applied to each item in the search output, as follows.

- Language (must be in English).
- Population (For question 6b, must be about older people with learning disabilities, their families or supporters. Note that in line with the scope, a specific age limit will not be used to define older people so a flexible and pragmatic approach to screening on the target population will be taken. For question 6c, must be about social care practitioners involved in delivering care and support at home to older people with learning disabilities.)
- Intervention (must be about care planning and support for older people with learning disabilities to maintain relationships with family, friends and local communities and improve access to volunteering, employment and adult learning, social and leisure activities, transport and technology).

- Setting (Must be people's own homes, family homes and temporary accommodation such as hostels and respite arrangements; supported living, residential and nursing care homes, including hospices). Primary healthcare, outpatients and community hospitals.)
- Country (must be UK or other OECD).
- Date (must not be published before 2005).
- Type of evidence (must be research).

Title and abstract of all research outputs were screened against these exclusion criteria. Those included at this stage were marked for relevance to specific review questions and retrieved as full texts.

Full texts were again reviewed for relevance and research design. A list of studies excluded on full text can be found in Appendix A, organised by exclusion criteria.

If still included, critical appraisal (against NICE tools) and data extraction (against a coding set developed to reflect the review questions) was carried out. The coding was all conducted within EPPI Reviewer 4, and formed the basis of the analysis and evidence tables. All processes were quality assured by double coding of queries, and of a random sample of 10%.

See Appendix B for full critical appraisal and findings tables.

Overview of evidence

In our initial screen (on title and abstract) we found 53 studies which appeared relevant to review question 6. We reviewed full texts and included a total of 9 papers. A small amount of studies provided effectiveness data (n=3) and they were all rated as moderate in terms of their internal validity. There was no cost-effectiveness evidence. Five studies provided data about the views and experiences of older people with learning disabilities and their families, carers and advocates. Their internal validity was moderate to good. Only 1 moderate quality study reported the views and experiences of practitioners. The issue of retirement was addressed in both effectiveness and views and experiences studies and there was also a small amount of effectiveness evidence about physical training programmes. There was only a small amount of data to improve understanding about access to transport and technology and this is reflected in the research recommendation on the role of technology.

Narrative summary of the evidence

In this section, a narrative summary of each included study is provided, followed by a synthesis of the evidence, according to the key outcomes, themes or sub-groups in the form of evidence statements [p148]. The approach to synthesising evidence was informed by the PICO within the review protocol.

The following studies provide data about care planning and support for older people with learning disabilities to access volunteering, social and leisure activities, transport and technology and maintain relationships with family, friends and within their local community.

a) Effectiveness evidence

Note that due to the heterogeneity of the evidence (the studies delivered different interventions to differing populations for differing lengths of time and used different outcome measures), data from each effectiveness study are presented separately, rather than combining them into a single meta-analysis.

1. Brooker K, van Dooren K, McPherson L et al. (2014) A systematic review of interventions aiming to improve involvement in physical activity among adults with intellectual disability. Journal of Physical Activity and Health 12: 434–44

Methods: Systematic review

Data: Quantitative

Country: Mixed, USA and UK

Outline

This systematic review (n=6 studies, 856 participants) was considered to be of moderate relevance to the review question (+) and moderate in terms of methodological quality (+). The study reviewed and assessed the impact of physical activity (PA) programmes in improving activity level and increasing exercise participation in adults with intellectual disabilities.

Findings

The PA programmes of the 6 included studies varied, ranging from health education (with discussion and goal-setting) or health promotion programmes with PA, nutrition, and weight loss components, delivered by health educators/professionals/peer mentors in groups in community settings, or individually at home visits. Durations and frequency of the PA programmes also varied, ranging from twice weekly to once every 2–3 weeks, lasting 30–120 minutes per session for periods of 8 weeks to 6 months.

The outcomes assessed were frequency and duration of PA. Three of the 6 studies showed significant improvement in PA frequency and duration:

Study 1 (n=44): Pre-and post-test frequency: 3.2 vs 3.9 times/week, p<0.01; pre- and post-test duration: 133 vs 206 mins/week, p=0.002;Study 2 (n=192): Pre-and post-test frequency: 3.24 vs 4.6 times/week, p<0.01;

Study 3 (n=54): Pre-and post-test % of mean time spent in light intensity of PA: 10.4 vs 12.3 mins/day, p<0.027; Pre-and post-test % of mean time spent in sedentary behaviour: 87.5 vs 84.9 mins/day, p=0.012.

Overall, the small number of included studies were methodologically weak with small sample and poor reporting, the effectiveness of intervention aiming to improve physical activity level in adults with intellectual disabilities could not be determined. However, the evidence suggests that PA interventions have had some success and have the potential to improve the health and wellbeing of people with intellectual disability.

2. Carmeli E, Orbach I, Zinger-Vaknin T et al. (2008) Physical training and well-being in older adults with mild intellectual disability: a residential care study. Journal of Applied Research in Intellectual Disabilities 21: 457–65

Method: Quantitative

Data: Effectiveness

Country: Israel

Outline

The study evaluated physical training in older adults with intellectual disability. This study was judged to have moderate relevance to the review area (+) and to be of moderate quality (+). The study aimed to investigate the effect of physical training on general wellbeing and self-image in older people with intellectual disability. The study employed a non-randomly selected, age and gender matched control group to compare the effectiveness of physical training on wellbeing. A total of 62 participants were enrolled. The exercise group included 23 women and 8 men, ranging from 47 to 67 years of age. The intervention physical training programme sessions were of 40-45 minutes each, performed 3 days a week for 10 consecutive months. There were 3 main outcome measures: body mass index (BMI), self-perception profile of wellbeing and Nottingham Health Profile (NHP). Participants were evaluated prior to the intervention and followed up 5 months after the training and at the end of the training programme.

Findings

The overall results showed no change in BMI, but showed a change in self-perception of wellbeing as evaluated by the NHP.

An analysis of variance shows a significant difference in groups in 2 specific domains evaluated using the self-perception profile of wellbeing.

- Social acceptance F=8.79; df 2; $p < 0.05$;

- Physical appearance F=3.15, df 2; $p=0.05$.

The 2 groups were compared according to NHP wellbeing scores at the beginning and at the conclusion of the study. The changes in scores of the wellbeing questionnaire were higher in the exercise group. Physical exercise resulted in significant positive changes in relation to 3 basic dimensions of NHP: energy, social isolation and physical mobility ($p=0.001$).

3. Stancliffe RJ, Bigby C, Balandin S et al. (2015) Transition to retirement and participation in mainstream community groups using active mentoring: a

feasibility and outcomes evaluation with a matched comparison group. Journal of Intellectual Disability Research 59: 703–18

Method: Quantitative

Data: Effectiveness

Country: Australia

Outline

This Australian study was judged to have moderate relevance to the review area (+) and be of moderate methodological quality (+). This quantitative controlled evaluation examined the feasibility of supporting older adults with learning disabilities to attend a mainstream community group as a transition to retirement. Each intervention–comparison pair was matched as closely as possible on work/day programme placement, full-time or part-time work status or day programme attendance, living arrangements, gender and age group.

The 58 participants’ age averaged 55.6 years (sd=6.6, range 44.1 to 72.2 years) and they consisted of 42 males and 16 females with mild and moderate intellectual disability. The intervention programme to support older people with learning disabilities to participate in mainstream community activities consisted of several components, such as individual retirement planning meetings, locating a community group or volunteering opportunity, attending the group, training mentors, activity restructuring, monitoring and ongoing support. Mentors were existing members of the community groups who volunteered to receive training and to support the participant when he/she was attending their group. There were 73 mentors (38 women, 35 men) for 26 intervention group participants. Outcomes assessed were participants’ loneliness, social satisfaction, depression, life events, quality of life, community participation, social contacts, and work hours before and 6 months after joining a community group.

Findings

Outcomes for the intervention group

A number of outcomes were assessed for the intervention group only.

1. Attending community groups

Overall, 27 of the 29 intervention participants (93%) joined a community group and attended for at least 3 months, with 25 (86 %) attending for a full 6 months.

2. Hours

Participants attended their group during the day on a weekday for 1–6 hours (average 3.6h, n=27). Several extended their involvement in community groups.

3. Meals and snacks

Every group had a shared morning tea, providing a key opportunity for social interaction. Of the 27 participants, 8 (30%) attended groups where there was no lunch or participants provided their own lunch.

4. Social contact outside of the group

Few participants had contact with community group members outside of group meeting hours.

5. Ongoing attendance

Most participants continued to attend their community group long after the post-test.

4. Community group participation

Intervention participants' weekly hours of participation in mainstream community groups increased from an average of 2.18 (sd=3.08) hours at pre-test to 5.35 (sd=3.83) hours at post-test, t=(1,25 =-7.87, p<0.001, d=1.54.

5. Social contacts

Time spent with new social contacts increased from 0.03 (sd=0.13) hours per week at pre-test to 3.30 (sd=1.64) hours at post-test, t(1,24)=-9.94, p<0.001, d=1.98.

6. Change in work hours

Overall, the participants reduced their weekly work hours from an average of 26.64 (sd=9.77) hours to 22.54 hours, a significant reduction, t(1,25)=3.44, p=0.002, d=0.67.

7. Retirement

Three intervention participants (10%) retired fully during the course of the research project.

Outcomes: comparing intervention and comparison group participants. Self-report variables.

1. Depression

None of the depression assessments revealed a significant group difference. The low mean pre-test scores on all of the depression scales meant that there was very little room for improvement.

GDS and Mini PAS-ADD Depression (n=47), f(1,44)=0.03, p=0.86, d=0.28

2. Loneliness

There was no significant between-group difference in self-reported loneliness in response to either the Modified Worker Loneliness Questionnaire or the UCLA Loneliness Scale.

MWLQ Aloneness (n=45), f(1,42)=1.40, p=0.24, d=-0.15

UCLA Loneliness (n=20), f(1,17)=1.72, p=0.21, d=-0.28

3. Social satisfaction

Intervention participants were significantly more socially satisfied at post-test than the comparison group.

Social satisfaction (n=46), f(1,43) =10.61, p=0.002, d=0.78

4. Quality of life

There was no significant between-group difference in self-reported quality of life for either the physical or mental subscales of the SF-36.

Quality of life (physical) (n=34), f(1,31)=0.55, p=0.47, d=0.21

Quality of life (mental) (n=34), f(1,31)=0.37, p=0.55, d =-0.36

5. Life events as a moderator variable

The analysis also revealed a significant main effect for the TTR intervention, F1, 31=6.49, p=0.016, showing that intervention group participants were less depressed at post-test (mean=1.65) than comparison participants (mean=3.25).

Depression scores differed significantly by life events group, F1, 31=9.96, p=0.004, with those with low life events being less depressed. Overall, these findings suggest that life events served as a moderator variable in this case, with the TTR intervention having protective effects on depression for individuals experiencing multiple life events.

Proxy report variables

GDS Depression (n=36), f(1,33)=2.98, p=0.095, d=-0.51

Mini PAS-ADD Depression (n=42), F (1,33) =2.76, p=0.105, d =−0.36

Mini PAS-ADD Life events (n=42), f(1,39)=0.14, p=0.71, d=0.03

(b) Data about the views and experiences of older people with learning disabilities

4. IDSTILDA The Intellectual Disability Supplement to the Irish Lo. (2014). Advancing Years, Different Challenges: Wave 2 IDS-TILDA. Findings on the ageing of people with an intellectual disability. University of Dublin, Trinity College, Available at: http://www.idstilda.tcd.ie/assets/pdf/Wave_2_Report_October_2014.pdf

Methods: Survey

Data: Views and experiences

Country: Republic of Ireland

Outline

This survey (IDSTILDA [The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing] 2014, n=708) was considered to be of good relevance to the review question (++), with moderate methodological quality (+). The study (Wave 2) is part of a longitudinal study following the previous study (Wave 1 in 2008) to document the changes over time of people with intellectual disability in Ireland. This study used questionnaires and extensive face-to-face computer assisted personal interviews to collect quantitative data from older people with different levels of intellectual disability or their proxies about their experiences on social participation, family relationships, access to and engagement with social activities, access to education, employment and information technologies (1 of 4 research areas addressed by this study).

Findings

The survey identified the following broad findings in terms of social participation and connections for adults with learning disabilities.

1. Adults with learning disabilities were reliant on siblings and extended families to provide their family network and support.

2. They lived in different neighbourhoods than their families/relations and this made it difficult to maintain connections.

3. They had reduced regular contact with family members and close friends.

4. They found other social partners such as paid staff more important as confidants in their lives.

5. Women with learning disabilities were more likely to feel socially excluded than men.

6. Those in community group homes and institutional residences were more likely to experience social exclusion than those in independent family residences.

7. Purposeful contact with families, friends and neighbours was greatly influenced by the level of learning disability, types of residence and age.

8. Engagement in social activities declined for the following the following people; men, people with profound learning disabilities, those aged over 65 and those living in institutional residences. These groups were also unlikely to be able to travel around in their local community.

9. Employment status remained poor and was exacerbated by issues of numeracy, literacy and money management.

10. Few older people with learning disabilities have benefited currently from access to information technologies.

The study suggests that to support a greater level of genuine integration and improve the quality of life of older people with learning disabilities, renewed efforts are needed in terms of reorganising group homes and employment programmes to facilitate and maintain social inclusion, opportunities for friendship and participation in meaningful social activities.

5. McCarron M, Swinburne J, Burke E et al. (2011) Growing older with an intellectual disability in Ireland 2011. First results from the intellectual disability supplement to the Irish Longitudinal Study on Ageing. Dublin: School of Nursing and Midwifery, Trinity College Dublin, available at: http://www.idstilda.tcd.ie/info/assets/pdf/ids_tilda_report_2011.pdf

Method: Survey

Data: Views and experiences

Country: Republic of Ireland

Outline

This nationally representative survey conducted in Ireland was judged to have moderate relevance to the review area (++) and to be of good methodological quality (++). This descriptive survey was conducted to identify the principal influences on successful ageing in people with a learning disability, and then determine if they are the same as or different from the influences for the general population. Further, the study intended to develop a first wave baseline picture of ageing among people with learning disabilities and a cohort of subjects that may then be followed longitudinally.

The age of 753 people with learning disabilities ranged from 41–90 years, with an average age of 54.7 years. A total of 45% were male and 55% female, and most participants were Roman Catholic (96%). All levels of learning disability were represented in the sample, with the highest number of participants (44%) falling within the moderate range of learning disability. The report covers several domains such as economic, social, mental health, physical health and beliefs about ageing. The reviewers focused on selected areas of the report to align with review question 6, such as relationships with family and communities, volunteering, social and leisure activities, employment and retirement.

Findings

1. Adults with an intellectual disability ageing in Ireland as members of their families and communities

People with an intellectual disability living in community settings participated in their local communities more than people living in residential centres. However, regardless of residential circumstances, adults with an intellectual disability in Ireland were not actively engaged with their communities and community presence was not actually equated with ‘living’ in the community. Given that those currently living in community settings tend to be younger, this does not bode well for community participation as they age and experience health decline.

Social networks – family members: the majority of adults had some level of contact with at least 1 family member. However, approximately 1 in 4 adults reported meeting their family once a year or less (27.7%) and 8% reported that they never meet family members. People with a mild to moderate intellectual disability (53%) tended to meet their family on a more regular basis (3 to 4 times per week, weekly or monthly) than those with a severe to profound intellectual disability (40.8%).

Over 3/4 of adults (75%) with an intellectual disability reported that they never wrote, texted, emailed or used social media tools such as Facebook to contact their family or friends. Moreover, less than 60% used the telephone to make such contacts. A large number of respondents (42.5%) had no phone contact with their family, with 9% of this group indicating that this question was not relevant.

Meeting friends: of great concern was the finding that 37% of adults with an intellectual disability in Ireland reported never meeting their friends; among this sub-group, 50% were within the mild to moderate intellectual disability levels. Contact also varied by residential circumstances: 72% (n=42) of those without contact lived in a residential setting; 22% (n=13) in a community setting; and 6% (n=3) were living independently or with their family. The majority of participants indicated that they never spoke on the telephone (58%, n=432) or wrote (73%, n=548) to their friends.

Loneliness and inclusion: of those who reported loneliness, 15% (n=29) reported feeling lonely most of the time, a majority of 74% (n=142) felt lonely sometimes, and a further 10% (n=20) said they occasionally felt lonely. Those living in community-based settings including group homes, independent living and with families were more likely to report experiencing at least some loneliness. This was particularly the case among those in the younger age groups.

Experience of inclusion: self-reporting participants were asked if they ever felt left out, and approximately a third (34%, n=140) reported experiences of feeling left out most of the time (12%, n=16), sometimes (74%, n=103) and rarely (14%, n=19).

Making friends: participants were asked if they found it difficult to make friends and 1 in 3 (32%, n=132) reported such difficulty.

Social engagement – voting: approximately 70% of adults with an intellectual disability in Ireland did not vote in the last general election. Those living at home or independently were more likely to vote than those living in a community group home, or in a residential centre, at 61.2%, 41.4% and 12.1% respectively.

Holidays: 3/4 of adults with an intellectual disability reported going on a holiday last year, with 17% going abroad. People with a more severe intellectual disability were less likely to go on holiday and more often went on day trips. With regard to holidays, 53% reported that they went on holiday in Ireland in the last year and 17% reported they holidayed abroad. People living in a community group home (66%, n=177) were more likely to holiday in Ireland than those living independently (57.4%, n=74) or within a residential centre (41.9%, n=149). However, people who lived independently or with their family (36.4%, n=47) were more likely to go on a foreign holiday than those living in a community setting (23.5%, n=63) or in a residential centre (5.3%, n=19).

Internet access: overall, 7.3% (n=55) reported that they had used the internet in the last year and of those who had, the majority (n=48) were within the mild to moderate range. In addition, 23% (n=172) of people mainly mild to moderate intellectual disability reported that they owned their own mobile phone.

Hobbies and activities: most adults with an intellectual disability (61%) had a hobby, engaged in daytime activity and leisure pursuits on a regular basis, and had social contacts with others.

Watching television: 81.5% of adults with an intellectual disability watched TV at least once a week.

Engaging in community life – neighbours and community inclusion: in this study, 14.7% (n=111) received help from their neighbour over the past 2 years. Of those who received help, 40.5% (n=45) lived at home or independently, 31.5% (n=35) lived in a community setting and 27.9% (n=31) were in a residential centre. A total of 13.1% (n=97) gave help to their neighbours. Among this group, 44.3% (n=43) lived at home or independently, 33% (n=32) lived in a community setting and 22.7% (n=22) lived in a residential setting.

Member of an organisation or club: respondents were asked to identify, from a list of options, the clubs, societies or organisations to which they belonged. Special Olympics ranked the highest, reported by 19% (n=145). Advocacy groups were next at 12% (n=92), followed by church/religious groups at 11% (n=81). Respondents were less likely to report engaging in education/music or evening classes (10%, n=75), or retirement clubs (4.2%, n=32) with very few (2.3%, n=17) reporting they were members of tenants or residents' associations. A number of respondents (4.1%, n=31) reported being a member of the Arch Club, 11 were members of a charitable association and 3 were members of a political party.

It is evident that age group, level of intellectual disability and living circumstances all have some influence on a person's engagement in leisure activities. People aged between 50–64 years were more likely to eat out (90%), go for coffee (88%) or go to the pub (70%), whereas for people aged 40-49 years, going shopping (86%) was the most commonly engaged in activity. For people aged 65 years and over, going to church (80.6%) and to the hairdressers (81.3%) were the most popular activities.

The majority of respondents (79%) identified their key worker/support staff as the main person with whom they engaged in leisure activities. In addition, a further 57% reported engaging in these activities with friends within their house, and 34% reported engaging in these activities with their family. Overall, only 30% reported engaging in these activities with friends outside the house. Respondents reported quite regular engagement, with 80.8% reporting going out to the cinema every few months or more, 52.1% going shopping at least once a week and 46.2% going to the pub for a drink once a week or less. Over 60% expressed a wish to do more activities, particularly gardening, boating, bowling or keeping fit.

Difficulties participating in social activities outside the home: over 50% of adults with an intellectual disability reported having difficulty in participating in social activities outside their home, with greatest difficulties being the need to have someone's assistance (44.2%) and health considerations (26%). Generally, people living independently/with their family (30.4%) or in a community setting (43.3%) reported less difficulty than those living in a residential centre (65.3%).

Difficulties getting around the community: although a sizable proportion of respondents (42.1%, n=313), reported they did not experience any difficulty getting around their community, almost 60% did; 38.2% (n=284) reported a lot of difficulty here and a further 19.7% (n=147) reported that this was not applicable to them, because they did not travel around their community.

Further examination identified that those living in a community setting experienced the greatest level of difficulty with 22.3% (n=25) having difficulty due to a lack of street crossings, 33% (n=37) having problems with signage, and a further 29.5% (n=33) feeling unsafe. In contrast 30.6% (n=53) of people living in a residential setting had difficulty with footpath design and surfaces. Finally, 14.3% (n=4) people living independently experienced the greatest level of difficulty in accessing recreational areas.

Transportation: people were asked to identify the means of transport they utilised within the past year. The majority of people (90%, n=678) identified being driven as a passenger by service staff as the means of transport they used most often. In total, 20.6% (n=155) reported using the public bus and 2.8% (n=21) used the public bus in rural settings. Interestingly, 37.7% (n=244) of participants reported a lack of transportation within their community. The majority of adults with an intellectual disability were dependent upon others for transportation and other assistance to access community options. Participants reported that their need for such assistance was the greatest barrier to successfully participating in social activities.

Voluntary work: numbers volunteering (7.7%; n=58) were smaller for adults with an intellectual disability, with the majority (63.2%, n=36) doing so twice a month or more. Reasons why people with an intellectual disability volunteered included enjoyment (8.5%, n=35), contributing something useful (7.9%, n=33), meeting other people (6.0%, n=25) and a sense of achievement and feeling needed (4.1%; n=17).

2. Employment, retirement, day services and lifelong learning

Overall, 6.6% (n=50) of Irish adults with an intellectual disability were in paid employment. Of those, 44% (n=22) received less than the minimum wage. Over half of respondents did not know how much money they received on a weekly/monthly basis. The majority of adults with an intellectual disability (79.4%) attended a day service, with 43.5% reporting they had choices in their activities at the centre and 32.7% reporting that they rarely or never had such choices. Just over a third (66.8%) reported that they received assistance going to and from their day service. A total of 15.6%, most of whom were aged 40–49 years, indicated that they were currently engaged in further education. For those who expressed a desire to engage in further education, computer and literacy classes were most frequently cited courses.

Employment status: only 23.1% (n=174) of the population surveyed described themselves as being in employment and 6.1% (n=46) reported being retired. A large number of respondents reported their day service or sheltered workshop as a place of employment; 33.3% (n=58) who described themselves as employed actually attended a day service or other kind of service and a further 37.9% (n=66) attended a sheltered workshop. In total, almost 3/4 (71.1%) of respondents reported their participation in some form of sheltered workshop or day service as employment.

Day services: overall, 79.4% (n=597) of respondents reported attending a day service, where the most popular activities were arts and crafts (76.7%), music (69%), and multisensory and other health therapies such as massage or occupational therapy (59.8%). In total, 43.5% (n=256) reported that they were usually able to choose the activities they engaged in, and a further 23.8% (n=140) reported that they got this opportunity sometimes; however, not everyone was happy with their day service. Almost a third (32.7%) reported that they rarely or never had the opportunity to choose activities.

Lifelong learning: the majority (84.5%) of adults with an intellectual disability were not engaged in further education, with only 15.4% (n=116) reporting that they had attended or were currently attending courses. Of those engaging in further education, 26.1% reported that their course was organised by the Vocational Education Committee (VEC), 11.3% by a training centre and 7.8% by a local community programme.

Retirement: 46 participants, most of whom were over 65 years, reported they were retired. The average preferred age of retirement was 62 years. Three-quarters

(75.4%) of those attending a day service reported they did not plan to retire from it at all and a further 12.2% of the total sample reported that they had already retired. Some respondents indicated they had no choice but to retire; as 1 participant reported, ‘when 50 you automatically retire from the day service’. A large number of adults with an intellectual disability indicated that they did not want to retire. Positive social consequences, including retaining contact with staff and friends and having somewhere to go during the day, are likely to be serious considerations in people’s decision not to retire.

6. Judge J, Walley R, Anderson B et al. (2010) Activity, aging, and retirement: the views of a group of scottish people with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities 7: 295–301

Method: Qualitative

Data: Views and experiences

Country: UK, Scotland

Outline

This qualitative study was judged to have moderate relevance to the review question (+) and to be moderate in terms of methodological quality (+). The study aimed to collect data to understand the views of older adults with learning disabilities in relation to their current daytime activity, which included but was not limited to day centre attendance. The study also sought to understand participants’ hopes and dreams about future daytime activity and the prospect of reaching ‘retirement’ age. The research was conducted in Scotland where 16 adults attending 3 different day centres were interviewed one-to-one in their own homes or in a private area of the day centre. Data were recorded and analysed using the interpretive phenomenological approach with the intention of giving a voice to participants in a traditionally under-researched area.

Findings

Results: 5 major themes were identified from the analysis.

1. The importance of being active

Most participants were clear about the importance of their activities both now and in the future. Being occupied was really important, giving them enjoyment and confidence. They felt strongly that they wanted this to continue and would even like to be doing more than they currently are: ‘They always tell me, you have to slow down when you get older, but I can’t see myself doing that ... I can’t see myself doing that because I just like to be on the move all the time ...’ (p297).

The participants often said their activity shouldn’t be limited to the day centre. They especially liked activities that had a purpose, for example voluntary work or work representing other service users. It gave them great confidence and a sense of achievement. So whereas participants were generally happy to be active, they were especially happy when the activity had meaning and purpose.

2. The day centre as a social hub

Many recognised that the day centre was really important in facilitating the activities that they felt were so important. The day centre was also a community in its own right: ‘you can mix in with people and you get new friends and all of that. You know ...c ommunity’ (p297).

Many had been attending the centre for years and built up strong friendships including with staff. The sense of community and friendship was described by many as the most important aspect of daytime activity. Participants were clearly worried that they would lose contact with friends when they are no longer allowed to attend the day centre: ‘if I wasn’t coming here I would be just staying in my bed, or just staying in my own home’ (p298).

3. Confusion concerning ‘retirement’

In Scotland, common practice is that adults with learning disabilities can attend day centres until they are aged 65, which is considered ‘retirement’ age. Participants were asked about their perceptions of ‘retirement’. Some were confused by the concept. Others understood what it meant in terms of day centre policy – but they were confused about the implications. For example, 1 respondent thought that although she wouldn’t be able to attend after she turned 65, she could still visit and another thought they would at least be able to have lunch at the day centre. For those who fully grasped the implications, their displeasure was evident, ‘No, no. Want to keep on coming I think ... I think I like to meet and mix with people ... talking to people’ (p298).

One of the participants reflected the fact that they have no choice in the matter of leaving the day centre and he commented, ‘it means you can’t go there any more ... so they’ll probably find you something else to do’ (p298). The researchers observed that having no choice about when to ‘retire’ (cease attending the day centre) was particularly upsetting because friendships, activities and opportunities are taken away and it is beyond people’s control. With retirement comes a loss of connectedness.

4. Desire for continuity

The general message was that participants didn’t want to stop their day centre attendance when they reached ‘retirement’. People wanted to keep going the way they are now – not least because they recognised the importance of continued activity and involvement as they age. When asked whether he would want to stop attending the day centre, 1 man said ‘No, all the time I want to come here’ (p298). Essentially all the participants were happy with their current routine and wanted to continue with the day centre and staying busy even when they reach 65.

5. The value of independence

In the context of ageing, respondents valued their independence and wanted it to continue. Some were determined to ensure this, for example 1 woman continuing to cook for herself (a skill she learned after her mother passed away). However, others were less optimistic about maintaining independence in their older age: ‘I hope I can stay in my own home ... I hope so … I don’t want to go into a home if I can help it’ (p299).

7. Newberry G, Martin C, Robbins L (2015) How do people with learning disabilities experience and make sense of the ageing process? British Journal of Learning Disabilities 43(4): 285–92

Method: Qualitative

Data: Views and experiences

Country: UK

Outline

This UK-based study is about exploring how people with learning disabilities experience and make sense of the ageing process and old age. This study was judged to have good relevance to the review area (++) and to be of good quality (++). Three women and 4 men with mild learning disability, aged 60–81, were recruited through community learning disability teams (CLDTs) and day services. Analysis was carried out using interpretative phenomenological analysis (IPA).

Findings

The main themes arising from the group analysis were as follows:

The quality of relationships is central to enjoyment of life, including subthemes on the importance of affection and companionship, distress at lack of closeness and anxiety about ability to satisfy others: ‘They’re very nice to me … If something was wrong, one of them would come and say “what’s wrong today?” and you’d be able to tell them’ (p288).

Powerlessness, which includes restricted autonomy, frustrated by dependency: ‘We have our own money, do your shopping, buy clothes, you didn’t do anything like that. Didn’t do it at [institution]’ (p289).

Needing a sense of purpose: participants wanted to continue working, learning and participating in activities, maintaining voluntary work, attending day services or doing housework: ‘They’re helping me to read and write at college and that’s helped me a lot. I’ll go into a shop now and ask people something’ (p288).

Making sense of getting older, including subthemes on reactions to changes with age, life review and looking to the future: ‘Some older people fall about and have to get sticks … They walk out and forget where they’re going. Forget where their home is … As you start to get older it [going to college] might change. Cause you might be vulnerable on the buses and that … My life is alright at the moment because I can get out and about and do things’ (p289).

8. Randell M, Cumella S (2009) People with an intellectual disability living in an intentional community. Journal of intellectual Disability Research 53: 716–26

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This qualitative study (n=15) was considered to be of good relevance to review question 6 (++) and moderate in terms of methodological quality (+). The study aimed to explore the views and experiences of people with intellectual disability (median age 50 years) living in an 'intentional community', a new form of community living aiming to provide a conducive and enabling environment, providing a full life for its members, comprising a cultural life, a community life and an economic life. The distinctive pattern of social relationships that exists in these intentional communities enabled people with intellectual disabilities to live alongside co-workers in big or small households, and have a working role to help in meeting the shared and individual needs of the community.

Findings

Overall, people with intellectual disability had positive experiences living in an intentional community in terms of:

- a sense of community, being able to share participation in making decisions, and economically sustaining the community
- feelings of being supported and being a useful member of a community that responds to their needs
- the facilitation of friendship with a high rate of social interactions with other people with intellectual disability
- high levels of meaningful employment
- a perceived sense of personal safety and absence of the overt subordination of residents to staff.

These advantages may be balanced by some loss of privacy. According to the researchers, the study suggests that these positive factors associated with living in an intentional community contrast with the experience of people with intellectual disability living in small homes funded on a contractual basis by public authorities, in which cost pressures often result in difficulties in staff retention and high staff turnover, with a negative impact on the quality of care provided.

c) Data about the views and experiences of practitioners

9. Zakrajsek GA, Hammel J, Scazzero JA (2014) Supporting people with intellectual and developmental disabilities to participate in their communities through support staff pilot intervention. Journal of Applied Research in Intellectual Disabilities 27: 154–62

Method: Mixed methods

Data: Effectiveness study

Country: USA

Outline

The study used mixed methods to evaluate a pilot support staff intervention conducted in the USA. This study was judged to have moderate relevance to the review area (+) and to be of moderate quality (+). The study aimed to develop and implement a pilot intervention specifically for staff members to increase their confidence in supporting choice and control of people with intellectual and developmental disabilities in community participation. The pilot had a single group of 36 participants, which includes staff and administrators. The intervention was held in the form of a 2-hour workshop hosted by 2 community agencies, occurring 3 times. The evaluation contained 2 main components: (i) quantitative pre/post-confidence measurements and (ii) qualitative feedback.

Findings

Quantitative

The results of the pre/post-test scores on the confidence surveys indicated a general trend towards participants scoring their confidence higher on the post-test than the pre-test.

Six items, out of a total of 7 items in the confidence scale, showed a significant positive effect at $p<0.001$, indicating that the intervention was effective. The 6 items were about confidence in understanding community participation programming with their agency, planning community participation activities, understanding and using strategies to support community participation, supporting the participants in documenting, assessing the barriers and supports and using issues to plan change. One item showed a similar increase in staff confident level in supporting people with intellectual disabilities to choose an activity in the community, but the change was not statistically significant ($p=0.172$).

Qualitative

Participants felt the intervention had an impact on supporting them to plan (more systematic, better prepared, tools to plan) community participation opportunities.

Participants also stated that the intervention positively influenced their relationship with clients when supporting community participation in terms of being more aware of options for support and giving them ideas of how to go about encouraging people.

Results also indicated that agencies may want to think about offering continued opportunities such as refresher courses to explore community participation strategies and resources in formal or informal ways.

Qualitative data also indicated that some changes could be made such as more time to practise skills – including role-playing – to make the intervention more effective.

Economics

No cost-effectiveness studies were identified and no additional economic analysis was undertaken for this review question.

Evidence statements

The evidence statements listed in this section synthesise the key themes across included studies.

R1	There is some evidence that older people with learning disabilities who live in residential settings are less well connected with friends and their local community than people living in their family home. The quality of the evidence is moderate to good. Analysis of the first wave of a longitudinal study in Ireland (McCarron et al. 2011 ++) found that people in residential settings had less contact with their friends, were more likely to report loneliness and had more

	difficulty participating in activities outside the home (p10). Analysis of the second wave of the same study (IDSTILDA 2014 +) found that people living in community group and residential homes were more likely to experience social exclusion and less likely to be engaged in social activities than people living in the family home (p9).
R2	There is some evidence that older people with learning disabilities have poor access to independent transport, which restricts their ability to participate in social activities. The quality of the evidence is moderate to good. Analysis of the first wave of a longitudinal study in Ireland (McCarron et al. 2011 ++) found that the majority of respondents were dependent on others for transport and other assistance to access community activities (p10). Analysis of the second wave of the same study (IDSTILDA 2014 +) found that engagement in social activities declined when older people (mainly men) with learning disabilities were unable to travel around their local community (p9).
R3	There is some evidence that older people with learning disabilities rely on paid staff as a key source of friendship. The quality of the evidence is mainly moderate. Analysis of the first wave of a longitudinal study in Ireland (McCarron et al. 2011 ++) found that the majority of respondents said their key worker was the person with whom they participated in leisure activities (p10). Analysis of the second wave of the same study (IDSTILDA 2014 +) found that where older people with learning disabilities had little contact with family and friends, they actually relied on pay staff to be their confidant (p9). A moderate quality Scottish study (Judge et al. 2010 +) found that older people with learning disabilities had developed strong relationships at their day centre and this included with members of staff, who had also often been holiday companions (p17).
R4	The is a moderate amount of evidence that older people with learning disabilities want to be involved in activities which they define as useful or meaningful. The quality of the evidence is moderate to good. Analysis of the first wave of a longitudinal study in Ireland (McCarron et al. 2011 ++) found that older people with learning disabilities who did voluntary work, did so because they felt they were contributing something useful and it made them feel needed (p10). A moderate quality Scottish study (Judge et al. 2010 +) found that older people with learning disabilities were generally happy to be active but particularly happy when the activity helped someone else or contributed, for example to the running of the day centre (p17). A good quality study (Newberry et al. 2015 ++) found that older people with learning disabilities needed a sense of purpose and they wanted this to involve working, learning or voluntary work (p20). A moderate quality evaluation (Randell and Cumella 2009 +) found that in a specially designed living environment for people with learning disabilities, residents felt good because they saw themselves as a useful member of the community (p21).
R5	There is some evidence that older people with learning disabilities do not want to stop their daily activities – e.g. work or volunteering – after they reach retirement age. The quality of the evidence is mainly good. Analysis of the first wave of a longitudinal study in Ireland (McCarron et al. 2011 ++) found that older people with learning disabilities did not want to 'retire' from their day centre, which they felt they would have to do when they reached a certain age, e.g. 50 years. They were particularly worried about losing relationships with staff and friends (p10). Similarly, a moderate quality Scottish study (Judge et al. 2010 +) found that older people with learning disabilities were very unhappy at the prospect of having to retire from their day centre at a certain age (in this case 65 years) (p17). A good quality study (Newberry et al. 2015 ++) found that older

	people with learning disabilities wanted to continue working, learning or doing voluntary work even after retirement age (p20).
R6	There is some evidence that older people with learning disabilities feel powerless in relation to decisions about their activities and relationships. The quality of the evidence is mainly moderate. A moderate quality Scottish study (Judge et al. 2010 +) found that older people with learning disabilities were particularly distressed at the prospect of retiring because they felt the decision was out of their hands and they had no choice about it (p17). A good quality study (Newberry et al. 2015 ++) found that people with learning disabilities felt powerless as they grew older and were restricted from making their own decisions (p20). A moderate quality evaluation (Randell and Cumella 2009 +) found that in a specially designed living environment for people with learning disabilities, residents felt good because they could participate in decision-making (p21).
R7	There is some evidence that exercise programmes for older people with learning disabilities help improve wellbeing and reduce social isolation. The quality of the evidence is moderate. A moderate quality study conducted in Israel (Carmeli et al. 2008 +) found that a physical training programme for people with learning disabilities could improve their perception of wellbeing (in terms of social acceptance and physical appearance) and also reduce their sense of social isolation (p3). A moderate quality systematic review (Brooker et al. 2014 +) suggests that physical activity classes improve health and wellbeing among older people with learning disabilities and given there were social components to the programmes, also help create relationships (p1).
R8	There is a small amount of evidence that a mainstream community support group helps the transition to retirement for older people with learning disabilities. The quality of the evidence is moderate. An Australian study (Stancliffe et al. 2015 +) found that during retirement, a community support group increased the amount of contact that older people with learning disabilities experienced. It also resulted in them being happier with their social connections compared with people who had not attended the group (p4).
R9	There is a small amount of evidence that training for practitioners helped them to support older people with learning disabilities to maintain connections with their community. A study by Zakrajsek et al. (2014 +) found that after a pilot training programme, staff were better at supporting choice and control among older people with learning disabilities in relation to community participation. In particular, they were able to identify and address the things that often prevent people being connected with friends and the community (p23).

Included studies for these review questions

Brooker K, van Dooren K, McPherson L et al. (2014) A systematic review of interventions aiming to improve involvement in physical activity among adults with intellectual disability. Journal of Physical Activity and Health 12: 434–44

Carmeli E, Orbach I, Zinger-Vaknin T et al. (2008) Physical training and well-being in older adults with mild intellectual disability: a residential care study. Journal of Applied Research in Intellectual Disabilities 21: 457–65

IDSTILDA The Intellectual Disability Supplement to the Irish Lo. (2014) Advancing Years, Different Challenges: Wave 2 IDS-TILDA. Findings on the ageing of people with an intellectual disability. University of Dublin, Trinity College, available at: http://www.idstilda.tcd.ie/assets/pdf/Wave_2_Report_October_2014.pdf

Judge J, Walley R, Anderson B et al. (2010) Activity, aging, and retirement: the views of a group of scottish people with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities 7: 295–301

McCarron M, Swinburne J, Burke E et al. (2011) Growing older with an intellectual disability in Ireland 2011. First results from the intellectual disability supplement to the Irish Longitudinal Study on Ageing. Dublin: School of Nursing and Midwifery, Trinity College Dublin, available at: http://www.idstilda.tcd.ie/info/assets/pdf/ids_tilda_report_2011.pdf

Newberry G, Martin C, Robbins L (2015) How do people with learning disabilities experience and make sense of the ageing process? British Journal of Learning Disabilities 43(4): 285–92

Randell M, Cumella S (2009) People with an intellectual disability living in an intentional community. Journal of intellectual Disability Research 53: 716–26

Stancliffe RJ, Bigby C, Balandin S et al. (2015) Transition to retirement and participation in mainstream community groups using active mentoring: a feasibility and outcomes evaluation with a matched comparison group. Journal of Intellectual Disability Research 59: 703–18

Zakrajsek GA, Hammel J, Scazzero JA (2014) Supporting people with intellectual and developmental disabilities to participate in their communities through support staff pilot intervention. Journal of Applied Research in Intellectual Disabilities 27: 154–62

3.6 Care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities

Introduction to the review questions

Review question 7, comprised of parts a, b and c, is reported in this sub-section. Part a sought data about the acceptability, effectiveness and cost-effectiveness of care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities. Part b was designed to locate the self-reported views and experiences of older people with learning disabilities, their families, carers and advocates about care and support at home and in supported housing. Finally, part c sought the views and experiences of people delivering, organising and commissioning social care, health and other services about care and support at home and in supported housing for older people with learning disabilities. This includes views on what works and what does not work well.

Review questions

7a. What is the acceptability, effectiveness and cost-effectiveness of care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities?

7b. What are the views and experiences of people using services and their carers in relation to care at home, in supported housing or accommodation with care and support for older people with learning disabilities?

7c. What are the views and experiences of health, social care and other practitioners about care and support at home, in supported housing or accommodation with care and support for older people with learning disabilities?

Summary of the review protocol

The protocol sought to identify studies that would:

- Identify the effectiveness and cost effectiveness of care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities.

- Identify emerging models and approaches to care and support at home for older people with learning disabilities and associated outcomes.
- Describe the self-reported views and experiences of older people with learning disabilities, their families and supporters about the care and support received at home, including what works and what does not work well.
- Consider specifically whether older people with learning disabilities, their families and supporters think that care at home is personalised and coordinated across health, social care and housing services.
- Describe the views and experiences of people delivering, organising and commissioning social care, health and housing services including what works and what does not work well in care and support at home for older people with learning disabilities.

Population

Older people with learning disabilities and care and support needs, their families, supporters and carers.

Social care practitioners (providers, workers, managers, social workers), housing practitioners and health and social care commissioners involved in delivering care and support at home to older people with learning disabilities.

Intervention

Care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities.

Setting

People’s own homes, family homes and temporary accommodation such as hostels and respite arrangements; supported living, residential and nursing care homes (including hospices). Primary healthcare, outpatients and community hospitals.

Outcomes

Person-focused outcomes (independence, choice and control over daily life; capability to achieve desired person-centred outcomes; user and carer satisfaction; continuity of care; health and social care-related quality of life, including carer quality of life; years of life saved) and service outcomes (use of health and social care services and housing support; need for support from health and social care practitioners and carers; delayed transfers of care from hospital; hospital admissions and readmissions; admission to care homes; length of stay in hospital and care homes). See 1.6 in the scope.

Study design

The study designs relevant to the ‘effectiveness and cost effectiveness’ part of this question included: systematic reviews of studies of care and support at home for older people with learning disabilities; randomised controlled trials (RCTs) of care and support at home for older people with learning disabilities; economic evaluations; quantitative and qualitative evaluations of different approaches; observational and descriptive studies of process; cohort studies, case control and before and after studies; mixed methods studies.

The study designs relevant to the views and experiences parts of this included: systematic reviews of qualitative studies on this topic; qualitative studies of user, carer and practitioner views of care and support at home; qualitative components of effectiveness and mixed methods studies; observational and cross-sectional survey studies of user or carer experience.

See Appendix A for full protocols.

How the literature was searched

One single search was conducted for all but 1 of the review questions (RQ 8: End of life care). Electronic databases in the research fields of health (including mental health), social care, social science and economics were searched using a range of controlled indexing and free-text search terms. Additional searches of websites of relevant organisations, and trials registries were undertaken to capture literature that may have been missed from the database searches. The search was based upon 2 concepts: a) older people, ageing and future planning, or aged care services; and b) intellectual or learning disabilities.

A wide range of search terms are used to find these 2 concepts. The search terms were developed from various methods. This included finding 52 items that related to the topic, and discovering relevant search terms.

See Appendix A for full details of the search.

How studies were selected

Search outputs (title and abstract only) were stored in EPPI Reviewer 4 – a software program developed for systematic review of large search outputs. Coding tools were applied and all papers were screened on title and abstract. Formal exclusion criteria were developed and applied to each item in the search output, as follows:

- Language (must be in English).
- Population. (For question 7b, must be about older people with learning disabilities, their families or supporters. Note that in line with the scope, a specific age limit will not be used to define older people so a flexible and pragmatic approach to screening on the target population will be taken. For question 7c, must be about Social care practitioners involved in delivering care and support at home to older people with learning disabilities.)
- Intervention (must be about care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities).
- Setting. (Must be people's own homes, family homes and temporary accommodation such as hostels and respite arrangements; supported living, residential and nursing care homes, including hospices. Primary healthcare, outpatients and community hospitals.)
- Country (must be UK or other OECD).
- Date (must not be published before 2005).
- Type of evidence (must be research).

Title and abstract of all research outputs were screened against these exclusion criteria. Those included at this stage were marked for relevance to specific review questions and retrieved as full texts.

Full texts were again reviewed for relevance and research design. A list of studies excluded on full text can be found in Appendix A, organised by exclusion criteria.

If still included, critical appraisal (against NICE tools) and data extraction (against a coding set developed to reflect the review questions) was carried out. The coding was all conducted within EPPI Reviewer 4, and formed the basis of the analysis and evidence tables. All processes were quality assured by double coding of queries, and of a random sample of 10%.

See Appendix B for full critical appraisal and findings tables.

Overview of evidence

In our initial screen (on title and abstract) we found 21 studies which appeared relevant to review question 7. We retrieved and reviewed full texts and included 7 papers and then in the update search an additional paper was located (Northway et al. 2016 +) bringing the total to 8 papers. There was very little effectiveness evidence, with data found in just 1 study. There was no cost-effectiveness evidence. Data on views and experiences were mainly from the practitioner perspective (5 studies), on supporting adults with learning disabilities in group homes as they grow older and supporting adults with learning disabilities in residential care for older people. There were gaps in evidence about the effectiveness, cost-effectiveness and experiences of care and support in the family home, which had implications for developing recommendations and drawing on other evidence, in particular expert testimony.

Narrative summary of the evidence

In this section, a narrative summary of each included study is provided, followed by a synthesis of the evidence, according to the key outcomes, themes or sub-groups in the form of evidence statements (p172). The approach to synthesising evidence was informed by the PICO within the review protocol.

The following studies provide data about the acceptability and effectiveness of care and support at home for older people with learning disabilities, the views of people using services and the views of practitioners about care and support at home for older people with learning disabilities.

a) Acceptability and effectiveness

1. Nambisan P, Lamkin D, DeLong C (2014) Feasibility, benefits and challenges of using telemonitoring for the aging with developmental disabilities (DD): an exploratory study. Online Journal of Public Health Informatics 6: e186

Methods: Mixed

Data: Effectiveness and views and experiences

Country: USA

Outline

This study from New York State, USA, was of moderate quality (+) and had some relevance to the review question (+). The authors wanted to investigate the benefits and challenges of telemonitoring for older patients with learning disabilities. Telemonitoring is a system installed at home that allows patients with health conditions needing regular monitoring to check their status (weight, blood pressure, glucose etc.) and transmit the results from there rather than go to a clinic for the checks. It allows patients and clinicians to monitor their status conveniently over periods of time. Twenty-one patients participated, and 25 of their care staff were trained to use the equipment. Those with greater functional independence were also trained to use the equipment themselves.

The authors used a mix of surveys and interviews to see how useful and acceptable telemonitoring could be. All 21 patients completed a questionnaire on 'quality of life' 6 months before its installation, and again 6 months later to see how their quality of life had changed. They also looked at medical records (admissions, conditions etc.) before and after to see if there were any effects on health service use. Around 6 months after installation the 25 care staff took part in some focus groups as did 6 of the more highly functioning patients, to explore their experiences of telemonitoring in more detail. The authors grouped together the different things that people said into similar types.

Findings

Survey and records – before and after: patients gave a better score on 2 out of 8 indicators in 'quality of life' questionnaire after telemonitoring systems were installed compared to before. When asked how much ‘does physical pain prevent you from doing things you need to do?’ they gave an average score of 4.45 (SD 0.51) before and 3.90 (SD 0.91) after ($p<0.05$). When asked ‘how healthy is your physical environment?’ they gave an average score of 3.77 (SD 0.92) before and 4.23 (SD 0.75) after ($p<0.05$). However for the rest of the questions there were no strong or consistent changes. Also there were no major changes in health conditions or number of doctors visits in medical records.

Patients’ focus group: the patients liked having the telemonitoring systems and said it made them feel more independent. It improved their knowledge of their own conditions, and if they saw a decline in results (for example, blood pressure, glucose) then they would change their behaviour over the next days to try and improve it. On the other hand there were sometimes functional problems with the machines that could make them annoying.

Care staff’s focus group: the care staff were very positive towards the systems and felt it was useful. They said it gave them more control and insight into the state of the patient. However, they felt it was most useful for those with higher functional independence (like those interviewed) but not so useful for those with lower functional independence.

b) Views of older people with learning disabilities/their carers and supporters

2. Forbat L (2008) Where should people with dementia live? Using the views of service users to inform models of care. British Journal of Learning Disabilities 36: 6–12

Method: Qualitative

Data: Views and experiences

Country: UK

Outline

This qualitative study was conducted in the UK and is of moderate quality (+) with some relevance to the review question (+). The study aimed to find out what people with learning disabilities in a residential setting know about dementia, how they saw their co-residents with dementia, and how those living with dementia perceived themselves and their needs. The most relevant facet of this study is that it gathered views and experiences directly from older people with learning disabilities. The researchers spoke to a group of 8 residents in a focus group style setting and conducted a further 8 interviews with residents with dementia. The study took place over 3 years, but it is not clear how often participants were interviewed. Participants were all group home residents with learning disabilities, they did not necessarily have dementia.

Findings

Service user views and experiences

The study identified several themes around dementia for people with learning disabilities in a residential home environment. These were: the symptoms, the effect of dementia on staff time, perceived special privileges and changes to the physical environment.

Symptoms

The study found that residents had some knowledge of peers developing dementia and of the symptoms. ‘Both two had problems they were wandering round the building, couldn’t see what they were going to do’ (p9). ‘Patricia couldn’t know how … couldn’t explain how she, she fell over had a fit in the cottage that time and didn’t remember it’ (p9).

Staff time

The study reports on residents’ comments about those who had dementia needing additional support from staff. Residents commented that it could negatively impact their time with staff: ‘Some of us feel as if we … I know it’s not right, but it makes some of us feel as though we need a few more staffing’ (p9). ‘Because of the way the one-to-one is on with Clare and er “I’m sorry I am doing the one-to-one with Clare” and if they are doing the one-to-one, it’s like they’ve got only so many different things to do’ (p9).

Special privileges

Participants commented that residents that were showing signs of dementia were given different treatment compared to other residents: ‘Maybe because the other one, she sees the other one that’s got dementia, gets away with sitting at the little coffee table ... getting her tea. And it makes her think “well if that one can get away with it, why can’t I?”” (p10).

The need for some residents to be away from the group while having meals was not understood by other residents and it was seen as preferential treatment.

Changes to the environment

The facility where the participants lived was set to be changed into specialised housing for people living with dementia. This news was not welcomed by current residents. ‘I don’t think Ronny, it’s like I said, Ronny doesn’t like to move’ (p10). ‘That means my flat’s going to get pulled down!’ (p10).

Residents were concerned about the changed to the physical environment, but the study does not link this concern to dementia, or residents who currently had dementia.

Residents with learning difficulties

The researchers spoke to 8 residents with dementia and the findings focus on interviews with just 2. Neither of those interviewed appear to have much awareness of the disease, apart from some mention of confusion and repeating themselves. They were aware they were taking prescribed drugs, but neither knew what the drugs were for. They showed some awareness of the ageing process and the need for some people to move to old people’s homes or care homes and showed some negativity at the prospect of such a move.

c) Views of practitioners

3. Bigby C, Webber R, Bowers B et al. (2008) A survey of people with intellectual disabilities living in residential aged care facilities in Victoria. Journal of Intellectual Disability Research 52: 404–14

Method: Mixed (survey)

Data: Views and experiences

Country: Australia

Outline

This paper reports the results of a survey of providers of aged residential care where adults with learning disabilities are being supported. Although it was conducted in Australia the study has good relevance to our review question (++), and it is judged to be of moderate quality (+). The survey is just the first phase of a 4-year study that aims to explore the pathways to residential care for adults with learning disabilities, the types of care and support provided to this group and the circumstances in which it may be appropriate for adults with learning disabilities to be supported in aged residential facilities. The survey reported in this paper mapped the population of adults with learning disabilities in aged residential care in Victoria, Australia, and asked specific questions about their characteristics, the reasons for moving to the facility and whether the facility seems to be the appropriate place for the adult with learning disabilities to be supported.

Findings

The characteristics of the adults with learning disabilities (age and condition), which were collated via the survey, have less relevance to this review question than other aspects of the findings. They are therefore not reported here but can be found in the evidence tables.

Reasons why adults with learning disabilities moved to aged residential care facilities: although not central to this review question, these data provide useful context. The main reason people moved to the aged care facilities was the inability of their previous facility to provide adequate support. When they were admitted from the family home (as in most cases), the main reason for admission was the death or ill health of the primary carer. Respondents said that for many people, residential care was the only option, ‘It seems to me that families hit a crisis [when the person has to be hospitalised]. They don’t know what to do so they decide on aged care as the only option but with good care the person often starts to feel better’ (p409).

The key question investigated in this study that had most relevance to our review is how appropriate is it for people with learning disabilities to be living in the aged care facility? This was explored in the study by establishing (a) the participation of residents in the local community and (b) the development of meaningful relationships:

Participation of residents in activities

The majority of residents with a learning disability (94%) took part in on-site activities at least weekly, with 73% participating daily. Authors note that there's no comparable data for rates of engagement for the general aged care population but that anecdotal evidence suggests that the rate is higher than this for both weekly and daily take-up. For residents who didn't participate, reasons given were: their health, cognitive incapacity, and emotional or behavioural difficulties. Some facilities had designed activities specifically for people with learning disabilities or encouraged them to get involved in the facility by doing jobs or taking on roles (collecting bread and mail, setting up rooms for activities).

Just under 50% of adults with learning disabilities participated in activities off site at least once a week. These included disability day programmes or outings with staff or friends/family. Sixteen per cent of residents (mostly under 60 years) continued to use disability services after admission in order to maintain engagement in activities. For some the cooperation between aged care and disability services seems to work well. However a number of respondents said that their resident with a learning disability was unable to access learning disability services because this would be 'double dipping' – for example, using funding from both aged and disability services. (Note: in Australia there are no firm policies about concurrent access to residential aged and disability services).

Development of meaningful relationships

A total of 28% of residents were reported as having no positive relationships with other residents. Notably, in the 'exceptional facilities' (meaning they have large numbers of learning disability residents) only 5% of residents were reported as not having positive relationships (compared with 28.7% in smaller facilities). Residents in the 2 exceptional facilities were twice as likely to have a close friendship with another resident. It wasn't unusual for residents with a learning disability to have friendships with staff rather than other residents.

Finally, the survey included an open-ended question about issues that arose in providing care to adults with learning disabilities in residential aged care. Three-quarters cited a range of difficulties. The most common issue was people with learning disabilities 'fitting in' with activities for other residents because of their younger age, different interests, 'difficult behaviours' or different care needs. Other issues were: the need for individual attention (24%), social isolation (11%), negative attitudes of other residents (6%), lack of appropriate staff training (6%) and shortages of resources to adapt to their needs (10%). 'The main issue is that most of the time, people are misplaced as they are usually younger than other residents. They have nothing in common with aged residents except that they can't look after themselves. It would be good if there were services outside for these people' (p411).

Note that the remaining 24% did not cite problems – they said care for the learning disabilities group was not dissimilar to the older residents or that differences had been accommodated.

4. Iacono T, Bigby C, Carling-Jenkins R et al. (2014) Taking each day as it comes: staff experiences of supporting people with Down syndrome and Alzheimer's disease in group homes. Journal of Intellectual Disability Research 58: 521–33

Method: Qualitative

Data: Views and experiences

Country: Australia

Outline

This Australian study aimed to report the experiences of staff that support people with Down's syndrome and dementia in group homes. This was a good quality study (++) and moderately relevant to our review question (+). Fifteen care staff, who cared for a total of 9 people with Down's syndrome and dementia, took part in the study. They each completed 2 interviews, about 6–12 months apart. In the interviews they were asked what was their understanding about what was happening to their residents; how had they responded to these changes; how they felt about these changes. The authors grouped together the different things that people said into themes.

Findings

What was their understanding of the changes? Overall, staff struggled to understand the change in their residents (for example, in their communication, personality, behaviours). They also struggled to understand that changes often fluctuated from day-to-day. They didn't consider whether these changes may in fact be caused by other factors like medication effects or depression. Some reported that they felt the resident wasn't necessarily 'different' since dementia, but that their personality came out much more strongly.

How had they responded to the changes? Overall, staff responded by taking each day as it comes. Mostly they tried to find ways to keep their resident calm and happy. They found it hard to predict what would be needed or what to expect in the future. If they found successful strategies for tasks they would try their best to spread it to other staff. Sometimes they would criticise other staff that weren't as good at handling the challenges.

How did they feel about the changes? Staff saw it as their responsibility to care for the residents as best they could. They worried that if the person was moved to a residential care home then they wouldn't get the specialist care for learning disabilities that they needed. However they were also not confident about their own skills, and felt sure the person would have to move away eventually. They doubted their organisation's commitment to providing the resources to keep them in place in the long term. Sometimes they sought help or advice from other services, but they could not always access it, and when they could they did not always trust the advice they were given.

5. Kåhlin I, Kjellberg A, Hagberg J (2015) Ageing in people with intellectual disability as it is understood by group home staff. Journal of Intellectual and Developmental Disability 41(1) 1–10

Method: Qualitative

Data: Views and experiences

Country: Sweden

Outline

This Swedish study was judged to be good quality (++) and moderately relevant (+) to the review question. It aimed to explore how staff understand and address issues around ageing in group homes for people with learning disabilities. The study interviewed 12 care staff working in group homes, each with between 7 and 9 residents. They were asked general questions about aging among people with learning disabilities, and about their experience of working with older people with learning disabilities. The authors used their previous knowledge to design the questions that each staff member was asked, but they could also ask further questions if anything interesting came up. The authors grouped together the different things that people said into similar types called themes, and wrote about these for their findings.

Findings

Care staff responses were grouped into 3 themes.

The silence of ageing

Ageing was rarely discussed by anyone in the homes. Residents rarely talked or thought about ageing. They cared about being identified as adults, but identifying as older wasn't important to them. Staff said the residents live in the present and are happy for each day, perhaps partly due to difficulties perceiving time passing. Staff themselves tended not to bring up ageing with residents, partly because it's generally a social taboo, but mostly because they felt residents had limited understanding of ageing. Staff only occasionally discussed ageing between each other. When they did it was mainly in relation to physical and mental aspects, as they affected their everyday work, or else on occasion during training.

Many faces of ageing

Ageing and learning disabilities had many aspects to it, many of which were similar to ageing in the general population but some were distinctly different. Many aspects of the medical/physical side were like the general population, such as decreased mobility or senses, health conditions and decreased memory or cognitive functions. However at the same time it could be especially hard to tell if any impairments were due to age related changes and not part of the lifelong learning disability. Also residents may lack awareness to notice changes in themselves, and may have trouble communicating any difficulties they're having, making them even harder to spot.

Ageing and learning disability and comparison to 'retiring' was often discussed. Some felt rather than a regulated age it is best seen as a gradual winding down of activities based on the resident’s abilities. Others believed there should be a ‘retirement’ age for people with learning disabilities, feeling that it was a question of equal opportunity, and occasionally reasoning that it was important to give room to younger people with learning disabilities.

Being in a state of readiness

Staff felt they now had to be constantly prepared for changes – although changes tended to be slow and gradual rather than sudden. Ageing meant they now had relationships with other support and care services. They had to make more decisions for their residents, and some felt this contradicted their professional role of supporting independence. They also had to be prepared for death, which required increased support and care in order to give a dignified end.

Although they were in a state of readiness they didn’t necessarily feel they were ready to act. Being in this state could be stressful; however it became easier with experience. Some staff were proud of their role of supporting dignity into later years, while others felt it made the job less rewarding, more monotonous and more concerned with care, cleaning etc. than supporting independence.

6. Maes B, Puyenbroeck J (2008) Adaptation of Flemish services to accommodate and support the aging of people with intellectual Disabilities. Journal of Policy and Practice in Intellectual Disabilities 5: 245–52

Methods: Qualitative (survey)

Data: Views and experiences

Country: Belgium

Outline

This Belgian study used a questionnaire to ascertain how services adapted to the needs of older people with learning difficulties, in terms of physical adaptations and staff qualifications and expertise. The study is relevant to the review question (++) and was well conducted (++). The questions explored how the services had adapted their working to suit the needs of this group, and staff views and experiences around the ageing of people with learning disabilities. The study was completed by 66 services (response rate 55%). There was no follow up.

Findings

Infrastructure and personnel: the study found that 66% of the sample who offered residential care to individuals with learning disabilities felt that their infrastructure was adapted to the meet the needs of older people with learning disabilities. The most common adaptations included 'wall grips, adapted bathroom equipment, accessibility of rooms for wheelchairs, adapted beds, lifting apparatus, and better lighting' (p247) and 'a stair lift, adapted furniture, call-up systems, and automatic doors' (p247).

Total 26% felt that they had adapted their services to meet the needs of people with learning disabilities, but not specifically older people, while 6% said they had not made adaptions for the needs for people with learning disabilities.

All the respondents to the questionnaire said that they had made adaptations to the needs of their residents through employing qualified staff. There were a variety of professionals working in the facilities where older people with learning disabilities lived. These included 'psychologists, therapists, and medical staff. In more than half of the services, nurses (58%) and older age support workers (58%)' (p247).

Facilities reported adapted their staffing levels to meet the needs of older people – 39% reported that they had a higher staff to patient ratio for older patients. This was because older patients tended to have greater needs, medically (45%), they had lost skills (41%) or had emotional needs (24%). Less common reasons included loss of mobility and additional day-care needs; 58% of respondents said that staff levels were insufficient to respond to the needs of older people with learning disabilities.

The study found that not many staff had received training in working with older people with learning disabilities.

Working methods: 59% of the respondents reported adapting support plans as people aged. Plans were most commonly revised every 2 years (40%) or yearly (35%); 25% were revised less than every 2 years. In 89% of cases it was reported that service users helped in the revision process.

There were diverse responses to a question about whether age should inform how residents are grouped in care facilities – 45% said it was an important factor and 47% said that it was not (others did not respond to the question). For those who deemed age unimportant this was because the residents had lived together for a significant amount of time already.

Few services had a specific programme for older residents. Most service users in the services questioned had their own activity programme. A large group of respondents felt that specific activities for the older people may be necessary (89%), but were unrealistic (44%). Some services did offer activities aimed at older residents such as: ‘vintage games, reminiscence, visiting old friends’. These happened in 73% of services.

Dementia was screened in 45% of the services, and more frequently among those suffering from Down’s syndrome. Palliative care was also organised in some services (64%).

Staff views and attitudes: the questionnaire asked staff to rate principles about supporting older people with learning disabilities.

Staff rated the following 5 as the most important (highest mean scores):

1. Social relations remain important when growing older.

2. Extending and maintaining social networks is very important for older persons.

3. We give older persons the opportunity to be inactive. A quieter pace is indicated.

4. We respect that older persons prefer to withdraw themselves especially towards younger persons.

5. It is important for older persons to remain independent, even when they lose certain functions like mobility, hearing, and sight.

The lowest scores were attributed to:

1. With older persons, we should focus on their past and their memories.

2. We focus on the ‘here and now,’ so that older persons keep their orientation on the current situation.

The study used exploratory factor analysis to identify solutions to the issues ranked as important by care staff. The factors were organised into 3 overarching groups.

‘Activating and socialising’: stimulating older persons to remain physically and psychologically active; stimulating older persons to remain independent; giving older persons chances for new initiatives; stressing the importance of social relations; continuing the earlier pattern of activities; compensating ageing problems with assistive devices; making plans for the future; stressing the importance of extending and maintaining social relations.

‘Disengagement’: not forcing persons to participate in activities; not forcing persons to do things that they do not want to; giving older persons chances for being inactive; respecting the choice of older persons; stressing the importance of cosiness and familiarity in the environment.

‘Methodical approach’: stimulating persons by means of (non-)verbal instructions; focusing on the past and on memories; supporting orientation to current situation; stimulating reminiscence; respecting older persons’ choice to participate or not in activities; compensating aging problems with assistive devices.

7. Northway R, Holland-Hart D, Jenkins R (2016) Meeting the health needs of older people with intellectual disabilities: exploring the experiences of residential social care staff. Health & Social Care in the Community Health & Social Care in the Community 25(3) 923–31

Method: Qualitative

Data: Views and experiences (practitioners)

Country: UK

Outline

This Welsh study, of moderate quality (+), had good relevance to the review question (++). The study aimed to address a gap in knowledge about the role played by residential care staff, who are not required to have any specialist health training, in monitoring the changing healthcare needs of older people with learning disabilities, and advocating for them in healthcare contexts. The researchers conducted semi-structured interviews with 14 house managers, who are typically responsible for managing the staff teams of 1 or more supported living settings for older people with learning disabilities. The study does not provide information about the supported living settings that the participants manage. They are described as a purposive sample, meaning that they were specifically selected for interview by the researchers, although the selection criteria are not stated. The interviews were transcribed, and through a process of analysis 5 major themes emerged, 3 of which are reported in this paper.

Findings

1. The first major theme is ‘meeting health needs’. The study reported that residential staff encounter a range of health conditions among residents, most commonly (but not limited to) diabetes, infections, dementia and mental health problems.

Residential care workers are involved in recognising, monitoring and meeting health needs, and this includes promoting healthy lifestyles wherever possible. Examples were given of staff noticing changes in residents’ health needs, leading to checks by health professionals, and of staff monitoring for changes to people’s health, including watching for the side effects of medication.

Generally relationships with health professionals were positive, but there were some issues. Some GPs were reluctant to carry out annual health checks or to visit residents at home, and some hospital staff expected residential staff to provide 24-hour care to residents while they were in hospital, which could not be provided.

Keeping records of all health-related contacts was recognised as an important way of ensuring continuity of care and support when there are changes of care personnel, and some managers were trying to develop ‘health passports’ or ‘traffic light’ records that would accompany residents into hospital, providing important details about care and support needs. However, hospital staff did not always pay attention to this information.

2. The second major theme was ‘the consequences of ageing’. Residents could need more support and more time as a result of signs of ageing, such as cognitive decline, sensory loss, mobility problems and becoming generally slower. Participants were willing to support residents ageing in place, giving residents’ right to stay in

their own home as a reason for supporting this, as well as the difficulty of finding suitable alternative placements. However, due to the increasing costs of caring for less able people, as well as the impact on staff and other residents, there would come a point where it became necessary to move people on. Participants could sometimes help residents age in place by recognising the need for environmental adaptations, for example, a walk-in shower or different height toilet.

Some participants spoke about providing end of life care, even where this amounted to nursing care.

3. The third major theme was 'relationships', which was seen as key to meeting residents' needs. Knowing the person helped staff and health professionals to be sensitive to any health changes in residents, and provided a basis for effective working. However, appropriate boundaries within these relationships were important for protecting both staff and residents. Participants also felt that when they formed a positive relationship with health professionals it had a positive impact on the way residents' health concerns were dealt with. However, some participants had encountered health professionals who did not understand or respect the roles of residential staff.

The study concluded that 'there is an urgent need for greater planning for this client group to ensure that appropriate services are available when needed: changes are needed to both policy and practice' (p7).

8. Webber R, Bowers B, McKenzie-Green B (2010) Staff responses to age-related health changes in people with an intellectual disability in group homes. Disability and Society 25: 657–71

Method: Qualitative

Data: Views and experiences

Country: Australia

Outline

This study, conducted in Australia, aimed to explore how supervisors in group homes responded to age-related changes in their residents with learning disabilities. The study was of moderate quality (+) and was relevant to the review question (+). The study interviewed 10 supervisors from group homes that had up to 6 residents with learning disabilities. They were asked about their general beliefs towards the ageing of residents, and about their considerations and subsequent actions in previous cases where residents had shown age-related changes. The first participants were asked quite broad questions, but as the study progressed the questions became more specific in response to what had already been said. The technique of developing increasingly specific questions and looking for common themes that result is called dimensional analysis.

Findings

There were 2 types of views.

The supervisors could generally be split into 2 groups based on their overall philosophy towards the aging of residents. The ‘ageing in place’ group felt that residents should be able to stay in their ‘home’ right up until it was no longer feasible, and every adjustment possible should be made to prolong how long they could stay. The ‘active engagement’ group felt the purpose of the group home was to support physically active people to engage with wider society, and so it’s in the best interest of everyone that a resident is moved to residential care once they are no longer able to engage in this way.

Decision-making: who makes the decisions? Supervisors were ultimately responsible for deciding which residents should be considered for a move from the group home to residential care. They would consult direct care staff and family members, however none reported involving residents themselves in the decision.

Decision-making: what are the reasons? There were 3 types of changes that increased the likelihood of a decision to move a resident on to residential care:

- slowing down (for example, less stamina)
- physical conditions (for example, heart conditions, cancer, incontinence)
- cognitive/behavioural changes (for example, mood, personality, confusion).

Supervisors often assumed that behaviour changes or confusion were signs of age-related dementia, and overlooked other reasons like medication side-effects, depression, or other underlying medical causes.

Another key consideration was the resources required to keep a resident in place – primarily equipment needs (for example, mobility aids) and increased staffing. The 'ageing in place' supervisors advocated these resources, while 'active engagement' supervisors often rejected them. Regardless of beliefs, all supervisors felt that at some point their residents may require more intensive or skilled care than they could provide. Many were confused over what services were available to enable residents to stay at home. Several mentioned a lack of planning or coordination at a regional or national level.

Other key considerations for supervisors were the impact of age-related changes on the other residents (for example, waking others up at night, outings having to be cancelled), and an awareness of waiting lists and the need to move people on so new residents could be accommodated.

Economics

No cost-effectiveness studies were identified and no additional economic analysis was undertaken for this review question.

Evidence statements

The evidence statements listed in this section synthesise the key themes across included studies.

H1	There is moderate amount of evidence that older people with learning disabilities need particular adaptations, support and attention in their home environment. The quality of the evidence is mainly moderate. Forbat (2008 +) found that older people with learning disabilities living in residential care thought their co-residents with dementia needed extra support and attention as well as adaptations to the environment. Residents without dementia were often resentful that these adjustments were being made (p4). Staff in the Maes and Van Puyenbroeck study (2008 +) reported that they had made adaptations to support people with learning disabilities as they age, including higher staff ratios and more specialised staff as well as changes to the physical environment (p14). The study by Northway et al.(2016 +) reported that managers of supported living schemes made a range of adaptations to try and ensure that residents could remain in their home even as they grow older and develop greater needs. Sometimes this included the provision of end of life care. Bigby et al. (2008 +) also found that people with learning disabilities living in aged

	residential facilities require focused attention to respond to 'difficult' behaviour or different care needs (p7).
H2	There is a moderate amount of good quality evidence that staff lack the expertise and understanding to support older people with learning disabilities in their home environment. The study by Kåhlin et al. (2015 ++) found that staff in a learning disability group home tended not to address the issue of ageing directly with residents and found it hard to distinguish symptoms of ageing from symptoms of the development of the learning disability (p12). Iacono (2014 ++) found that staff in a learning disability group home did not necessarily have specific training or knowledge about older people with learning disabilities, instead dealing with them in an ad hoc manner, and they doubted their organisation's commitment to providing the required support to keep them in place long term (p10). Bigby et al. (2008 ++) found that 1 of the difficulties in supporting older people with learning disabilities in a residential setting for older people was a lack of training among staff. Respondents also explained that when older people with learning disabilities did not participate in activities, this could be because of emotional or behavioural difficulties, which suggests staff may not be sufficiently experienced to deal with these (p7). Maes and Van Puyenbroeck (2008 +) found that not many staff in residential services had received training in supporting older people with learning disabilities (p14).
H3	There is some moderate quality evidence that specific approaches to supporting older people with learning disabilities in residential settings are developed by staff. These approaches seem to improve people's experiences and quality of life. Maes and Van Puyenbroeck's study (2008 +) found that staff developed specific approaches to working with older people in residential learning disability settings with the aim of supporting them to maintain social connections but also have time alone as needed (p14). Webber et al. (2010 +) found that some providers of group homes believed people with learning disabilities should be able to 'age in place' and stay in their home for as long as possible and were willing to invest in staff and equipment to enable this (p17). Bigby et al (2008 +) reported that some aged care facilities had designed activities specifically for people with learning disabilities or encouraged them to get involved in the facility by doing jobs or taking on roles within the home (p7).
H4	There is a small amount of evidence that telemonitoring improves outcomes and experiences for older people with learning disabilities. The quality of that evidence is moderate. The study by Nambisan et al. (2014 +) found that telemonitoring helped residents understand their conditions better and made them feel more independent. Staff said it gave them greater insight into the condition of the residents (p1).
H5	There is some evidence that adults with learning disabilities can have poor experiences and quality of life when they live in residential care settings for older people. The quality of the evidence is mainly moderate. Bigby et al. (2008 +) reported that adults with learning disabilities often had no meaningful relationships with other residents, more often befriending staff. This is particularly the case where there are only a small number of adults with learning disabilities living in the care home (p7). Iacono (2014 ++) found that staff in group homes wanted their residents to stay as long as possible because they did not believe they would receive specialist care for learning disabilities if they moved to a care home (p10). Similarly, some respondents in the Webber study (2010 +) felt group home residents would be better supported there than in a residential home and said that every possible adjustment should be made so they could stay. On the other hand, some respondents felt that it was in

	everyone's best interests if people with learning disabilities move to residential care as they grow older and less independent (p17).
H6	There is some evidence that adults with learning disabilities move to care homes generally because the home environment in which they had been living can no longer meet their needs. The quality of that evidence is moderate. Bigby's (2008 +) survey findings showed that most older adults had moved to care homes from the family home because their carer had died or was in hospital. Where they had moved to a care home from another residential setting, it was due to the inability of that facility to provide adequate specialist support (p7). The group home supervisors in Webber et al. (2010 +) said the most frequent reasons people moved into residential care were physical conditions, losing stamina and cognitive problems. Almost all agreed there would come a point when all residents would require more intensive or skilled care than they could provide and would therefore have to move to residential care (p17). Similarly, group home staff in Iacono et al. (2014 ++) admitted that although it was against their better judgement, residents would inevitably have to move to care homes because they lacked the skills to provide specialist support (p10).
H7	No evidence was found from studies published since 2005 about the effectiveness or the experience of care and support for older people with learning disabilities living in the family home. Six of the included studies were based in residential settings – often group homes – for adults with learning disabilities: Nambisan (2014 +), Forbat (2008 +), Iacano (2014 ++), Kåhlin (2015 ++), Maes and Van Puyenbroeck (2008 ++) and Webber (2010 +). One of the included studies was based in residential settings for older people (Bigby 2008 +).

Included studies for these review questions

Bigby C, Webber R, Bowers B et al. (2008) A survey of people with intellectual disabilities living in residential aged care facilities in Victoria. Journal of Intellectual Disability Research 52: 404–14

Forbat L (2008) Where should people with dementia live? : Using the views of service users to inform models of care. British Journal of Learning Disabilities 36: 6–12

Iacono T, Bigby C, Carling-Jenkins R et al. (2014) Taking each day as it comes: staff experiences of supporting people with Down syndrome and Alzheimer's disease in group homes. Journal of Intellectual Disability Research 58: 521–33

Kåhlin I, Kjellberg A, Hagberg J (2015) Ageing in people with intellectual disability as it is understood by group home staff. Journal of Intellectual and Developmental Disability 41(1) 1–10

Maes B, Puyenbroeck J (2008) Adaptation of Flemish services to accommodate and support the aging of people with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities 5: 245–52

Nambisan P, Lamkin D, DeLong C (2014) Feasibility, benefits and challenges of using telemonitoring for the aging with developmental disabilities (DD): An exploratory study. Online Journal of Public Health Informatics 6: e186

Northway R, Holland-Hart D, Jenkins R (2016) Meeting the health needs of older people with intellectual disabilities: exploring the experiences of residential social care staff. Health & Social Care in the Community Health & Social Care in the Community 25(3): 923–31

Webber R, Bowers B, McKenzie-Green B (2010) Staff responses to age-related health changes in people with an intellectual disability in group homes. Disability and Society 25; 657–71

3.7 End of life care for older people with learning disabilities

Introduction to the review questions

Review question 8, comprised of parts a, b and c, is reported in this sub section. Part a sought data about the acceptability, effectiveness and cost-effectiveness of end of life care for older people with learning disabilities. Part b was designed to locate the self-reported views and experiences of older people with learning disabilities, their families, carers and advocates about end of life care. Finally, part c sought the views and experiences of people delivering, organising and commissioning social care, health and housing services about end of life care for older people with learning disabilities. This includes views on what works and what does not work well.

Review questions

8a. What is the effectiveness and cost-effectiveness of end of life care for older people with learning disabilities?

8b. What are the views and experiences of older people with learning disabilities and their carers in relation to end of life care?

8c. What are the views and experiences of health, social care and other practitioners about support for older people with learning disabilities at the end of life?

Summary of the review protocol

The protocol sought to identify studies that would:

- Identify the effectiveness and cost effectiveness of interventions or approaches to improve end of life care for older people with learning disabilities.
- Identify emerging models and approaches to improving end of life care for older people with learning disabilities and associated outcomes.
- Describe the self-reported views and experiences of older people with learning disabilities, their families and supporters about end of life care, including what works and what does not work well.
- Describe the views and experiences of people delivering, organising and commissioning social care, health and housing services about end of life care for older people with learning disabilities, including views on what works and what does not work well.

Population

Older people with learning disabilities and care and support needs, their families, supporters and carers.

Social care practitioners (providers, workers, managers, social workers), housing practitioners and health and social care commissioners involved in delivering care and support at home to older people with learning disabilities.

Intervention

End of life care for older people with learning disabilities.

Setting

People’s own homes, family homes and temporary accommodation such as hostels and respite arrangements; supported living, residential and nursing care homes (including hospices). Primary healthcare, outpatients and community hospitals.

Outcomes

Person-focused outcomes (independence, choice and control; capability to achieve desired person-centred outcomes; user and carer satisfaction; continuity of care; health and social care related quality of life, including carer quality of life) and service outcomes (use of health and social care services and housing support; need for support from health and social care practitioners and carers; delayed transfers of care from hospital; hospital admissions and readmissions; admission to care homes; length of stay in hospital and care homes).

Additional outcomes specific to this review question: pain and other symptoms, emotional and cognitive symptoms, spirituality, survival time and aggressiveness of care, advance care planning. See 1.6 in the scope.

Study design

The study designs relevant to the ‘effectiveness and cost effectiveness’ part of this question included: systematic reviews of studies of interventions to improve end of life care for older people with learning disabilities; randomised controlled trials (RCTs) of interventions to improve end of life care for older people with learning disabilities; economic evaluations; quantitative and qualitative evaluations of different approaches; observational and descriptive studies of process; cohort studies, case control and before and after studies; mixed methods studies.

The study designs relevant to the ‘views and experiences’ parts of this question included: systematic reviews of qualitative studies on this topic; qualitative studies of user, carer and practitioner views of interventions to improve end of life care for older people with learning disabilities; qualitative components of effectiveness and mixed methods studies; observational and cross-sectional survey studies of user or carer experience.

See Appendix A for full protocols.

How the literature was searched

A unique search was designed to find research literature relating to end of life care for people with learning disabilities. This intends to find studies on effectiveness and cost-effectiveness, and on views and experiences of older people with learning disabilities and their carers and health, social care and other practitioners.

Electronic databases in the research fields of health (including mental health), social care, social science and economics were searched using a range of controlled indexing and free-text search terms. Additional searches of websites of relevant organisations, and trials registries were undertaken to capture literature that may have been missed from the database searches. The search was based upon 2 concepts: a) people with learning disabilities, and b) end of life care, terminal illness, advance care planning.

A wide range of search terms were used to find these 2 concepts. The search terms were developed from various methods, including discovering search terms from other evidence reviews, test searches and from research we already found on this topic.

See Appendix A for full details of the search.

How studies were selected

Search outputs (title and abstract only) were stored in EPPI Reviewer 4 – a software program developed for systematic review of large search outputs. Coding tools were applied and all papers were screened on title and abstract. Formal exclusion criteria were developed and applied to each item in the search output, as follows:

- Language (must be in English).
- Population. (For question 8b, must be about older people with learning disabilities, their families or supporters. Note that in line with the scope, a specific age limit will not be used to define older people so a flexible and pragmatic approach to screening on the target population will be taken. For question 8c, must be about social care practitioners involved in delivering care and support at home to older people with learning disabilities.)
- Intervention (must be about end of life care and support for older people with learning disabilities).

- Setting. (Must be people’s own homes, family homes and temporary accommodation such as hostels and respite arrangements; supported living, residential and nursing care homes, including hospices. Primary healthcare, outpatients and community hospitals.)
- Country (must be UK or other OECD).
- Date (must not be published before 2005).
- Type of evidence (must be research).

Title and abstract of all research outputs were screened against these exclusion criteria. Those included at this stage were marked for relevance to the end of life care question and retrieved as full texts.

Full texts were again reviewed for relevance and research design. A list of studies excluded on full text can be found in Appendix A, organised by exclusion criteria.

If still included, critical appraisal (against NICE tools) and data extraction (against a coding set developed to reflect the review questions) was carried out. The coding was all conducted within EPPI Reviewer 4, and formed the basis of the analysis and evidence tables. All processes were quality assured by double coding of queries, and of a random sample of 10%.

See Appendix B for full critical appraisal and findings tables

Overview of evidence

In our initial screen (on title and abstract) we found 36 studies which appeared relevant to review question 8. We retrieved and then reviewed full texts and included a total of 11 papers. There was limited evidence about the views and experiences of older people with learning disabilities and their families (n=2) and no effectiveness or cost-effectiveness evidence. The 9 studies providing practitioner views were low to moderate in terms of internal validity.

Narrative summary of the evidence

In this section, a narrative summary of each included study is provided, followed by a synthesis of the evidence, according to the key outcomes, themes or sub-groups in the form of evidence statements (p198). The approach to synthesising evidence was informed by the PICO within the review protocol.

The following studies provide data about end of life care for older people with learning disabilities.

a) Evidence of effectiveness and cost-effectiveness

We did not locate any effectiveness or cost-effectiveness data but 1 of our included studies evaluated the process of an intervention, based on the views and experiences of health professionals who participated in the intervention (Cross et al. 2012). This paper is therefore presented under question 8c.

b) Evidence about the views and experiences of older people with learning disabilities and their family carers (note that some views of older people and families are also reported in one of the practitioner views papers, Tuffrey-Wijne et al. 2013)

1. McLaughlin D, Barr O, McIlfatrick S et al. (2014a) Service user perspectives on palliative care education for health and social care professionals supporting people with learning disabilities. BMJ Supportive & Palliative Care 5: 531–7

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This qualitative study, conducted in Northern Ireland, was considered to be of moderate relevance to the research question (+) and good in terms of methodological quality (++). The study aimed to explore the views and experiences of people with learning disabilities and their family carers on how they would like to be supported in palliative and end of life care. Qualitative data were collected using semi-structured interviews and focus groups from 17 people with learning disabilities and 5 family carers. For people with learning disabilities, a pictorial approach, using drawings and illustrations, was used to gather data.

Findings

Equity of access to end of life care services and unmet needs: this study showed that people with learning disabilities were able to talk about death and dying. They wanted to be able to access support and information around the illness, treatment and prognosis and this information needed to be provided in a format that they could understand. Equity of access to palliative care services was important for people with learning disability, and they really valued having friends and familiarity around them, such as their relationships with their pets and how they like to have them around, indicative of the holistic end of life support they preferred.

Family carers – family-centred care and bereavement support: there were unmet information and support needs for family carers of people with learning disabilities. Family carers appreciated a family-centred care approach because they felt that being familiar with a person with a learning disability, knowing what they liked, reflects the personhood and humanity of the person they cared for. Family carers also reported the need for family members to have bereavement support from a counsellor to talk about imminent losses of significant people.

Joint working and learning: views from people with learning disabilities and their family carers suggested that those needs could be met within a multidisciplinary team approach, such as collaborative working and learning between family carers, people with learning disability and services. These were also identified as educational priorities for doctors, nurses and other professionals in providing end of life care to this population.

c) Evidence about the views and experiences of practitioners

2. Bailey M, Doody O, Lyons R (2016) Surveying community-nursing support for persons with an intellectual disability and palliative care needs. British Journal of Learning Disabilities 44: 24–34

Methods: Quantitative and qualitative

Data: Views and experiences

Country: Republic of Ireland

Outline

This survey, conducted in the Republic of Ireland, was considered to be of moderate relevance to the research question (+) and low in terms of methodological quality (-). The study aimed to report views of 96 community nurses (public health nurses, community nurses, practice nurses, hospice at home nurses and palliative care nurses) about the provision of community nursing support for persons with an intellectual disability and palliative/end of life care needs. Both quantitative and qualitative data were collected using open-ended questionnaires.

Findings

Main barriers to end of life care provision – lack of skills and knowledge: Community nurses reported a lack of knowledge, understanding, confidence, communication skills and also a lack of resources as main barriers that hinder their end of life care giving to people with learning disabilities. Other limiting factors included late referrals and lack of time.

Collaborative working: the nurses emphasised the benefits of liaison between family and professional and nonprofessional carers, and collaborative working to promote the development of mutual understanding as to when and how to involve each other in the care process, crucial to ensure optimal palliative/end of life care for people with learning disabilities. These nurses reported that through teamwork, advance planning, knowing the person and best practice the provision of palliative/end of life care for people with learning disabilities would be improved.

In-service education: the majority of community nurses (65–75%) surveyed in this study identified in-service education and workshops as a means to support their educational needs and suggested lectures/workshops (70%) as their preferred mode of delivery.

3. Cartlidge D, Read S (2010) Exploring the needs of hospice staff supporting people with an intellectual disability: a UK perspective. International Journal of Palliative Nursing 16: 93–8

Method: Qualitative

Data: Views and experiences

Country: UK

Outline

This is a qualitative study which explores the views of hospice staff about their own needs for professional development to help them better support people with learning disabilities. The hospice is located in North Staffordshire and provides palliative and end of life care to people via a 28-bed hospice at home and day hospice service. The researchers gathered views via a questionnaire (26 out of 50 respondents) and they conducted a focus group involving seventeen hospice staff. The quality of the methodology has been rated as low (-) and the relevance to the review question is moderate (+).

Findings

Experience/expertise working with people with learning disabilities and their families: experience among nursing staff varied. They felt it was important to have access to learning about ‘good death’ from learning disability nurses to give them confidence and provide professional development. It was particularly helpful in teaching them how to manage and understand particular behaviours, about which they had had no specific training.

Importance of trust and building relationships: staff felt it was very rewarding caring for people with learning disabilities at the end of their lives. They said it was very important to get to know people and build up trust and confidence.

Communication: hospice staff found it difficult to discuss patients’ health status and treatment compliance issues with them. It was hard to make them understand their conditions and also difficult to gain valid consent. Particular challenges included getting to know the patient and adjusting communication to suit their individual needs. Having realised these difficulties, staff developed more effective ways of communicating, namely being patient and repeating things several times in different ways until the patient could absorb and understand the information.

Caring for someone with a learning disability at the end of life compared with caring for the ‘general population’: there were a number of similarities including, everyone is unique and individual, family dynamics are often challenging and staff should expect the unexpected. The differences included a lack of social skills among the learning disabled people, which was difficult to handle within the hospice setting (although this related to the behaviour of a family member of a dying person – rather than a patient).

Considerations: this study provides some useful insight into the views of hospice staff about supporting people with learning disabilities at the end of life, including about their need for training in this area. However Guideline Committee members should note that it was only judged to be moderately relevant because the population of focus was not specifically older people – although of course this could be implied.

The study methods also have weaknesses in relation to sampling, data collection and analysis and there is a lack of original data to support reported findings. Unfortunately these problems undermine the confidence we can have in the results and the Guideline Committee should keep this in mind during group discussions.

4. Cross H, Cameron M, Marsh S et al. (2012) Practical approaches toward improving end-of-life care for people with intellectual disabilities: effectiveness and sustainability. Journal of Palliative Medicine 15 (3) 322–6

Method: Qualitative

Data: Views and experiences of practitioners

Country: UK

Outline

This qualitative study, conducted in London, was considered to be moderately relevant (+) to the review question and low in terms of methodological quality (−) because it reported insufficient details. The study aimed to explore ways of increasing access to palliative care services for people with learning disabilities by implementing a project involving 4 hospices and 228 care homes. Evaluation data were collected using face-to-face, telephone interviews and focus groups with a wide range of stakeholders (project managers, trainers, link workers, delegates of the training programmes, hospice and care home staff and managers, number not reported).

Description of the intervention: the 3-year project involved 3 different approaches: (1) training of learning disability staff on basic end of life care; (2) training of palliative care staff on how best to meet the needs of people with learning disabilities; and (3) a link-worker scheme with a designated point of contact for support and information. The project ran a number of 2-day training courses, for learning disability staff and palliative care staff separately, which were located in each of the 4 hospices in the area.

The training aimed to teach palliative care staff about issues affecting people with learning disabilities that they might need to consider in providing palliative care for them, and to teach learning disability staff about palliative care. The project also established a link worker scheme in both work areas, whereby a member of staff in each community learning disability team and hospice was appointed to provide a contact point for information and support about palliative care for people with learning disabilities. Ten such appointments were made.

Findings

Attendance: there was low initial interest from palliative care staff in the training, which hospice directors stated was due to low numbers of referrals of people with learning disabilities. The researchers saw this as part of a ‘vicious cycle’ which the project did not manage to have an impact on: ‘low referrals into palliative care, reinforcing the unimportance of the area from the palliative care professionals’ perspective’ (p324). Two of the 4 hospices in the area withdrew from the project, although those staff who did attend the training rated it highly.

Forty-six out of 228 residential care homes that were identified within the catchment area sent staff on the training programmes. Care managers attended, and homes sent more staff as the project continued, with managers calling after the end of the project to request more training. Feedback presented in the report is very positive.

Evaluation: evaluation of the project was carried out by 2 independent evaluators.

Feedback on project: home care staff made good use of the training; learning disability community teams also benefited and were better informed about palliative care; views were mixed about whether it benefited palliative care professionals.

Most appreciated aspects about the training: reflecting on complex issues, thinking about difference and facing fears.

Less positive aspects: ‘both palliative care and learning disabilities were widely viewed as being rather forbidding and perhaps even frightening areas, each with its own unfamiliar language’ and that ‘the project mostly involved direct health and social care professionals, trainers, and voluntary sector organisations, not system managers and not local users and family carers. This might explain some of the problems experienced in partnership working’ (p325).

Lack of system support: the link worker scheme did not work well, described as having ‘mixed, but generally disappointing results’ (p324). Workers appointed to this role were not well supported by their organisations, and were not given a clear place in organisational structures. Participants were not clear about their role.

Lack of understanding: the study concluded that ‘in general, there was a lack of understanding of each other’s role between palliative care professionals and learning disability staff, with each unsure of what the other service is providing and how it is run’ (p325). People with learning disabilities were largely invisible to the hospice services involved.

Tensions: the study observed that there were tensions between specialist and generic working in both fields of work, which needed to be acknowledged before effective changes could take place. There was a view of people with learning disabilities as a minority wanting access to services, producing the tension of special support versus being in the mainstream.

5. McCarron M, McCallion P, Fahey-McCarthy E et al. (2010) Staff perceptions of essential prerequisites underpinning end-of-life care for persons with intellectual disability and advanced dementia. Journal of Policy and Practice in Intellectual Disabilities 7: 143–52

Method: Qualitative

Data: Views and experiences

Country: Republic of Ireland

Outline

This is a qualitative study, conducted in the Republic of Ireland with the aim of understanding the views and experiences of staff providing end of life care to people with learning disabilities and advanced dementia. The researchers conducted focus groups with 50 participants from 6 learning disability service providers and 1 specialist palliative care service. Thematic analysis of the findings from the focus groups was conducted with codes identified and then collapsed into core themes. The study has good relevance to the review question (++) and the quality of the methodology is moderate (+).

Note that 2 other papers reporting findings from the same study were ‘included’ in our screening. However after an appraisal of all 3 papers, this was chosen because it provides the greatest detail in terms of methodology and findings.

Findings

The person at the centre – knowing the person: knowing the person’s likes/dislikes was seen as being central to good dementia care. Respondents felt that learning disability services have a strong philosophy of person-centred care.

Maintaining relationships: keeping links with family and staff was seen as really important throughout the continuum/progress of dementia. So, for people living in community learning disability settings, this would often mean that staff working there would not want the person to be moved on to a specialist palliative care setting. If people were transferred, staff from the learning disability unit would often visit and bring friends/residents from the unit, ensuring the person doesn’t die alone: ‘... the service does ensure somebody regular would be with the resident ... can spend time with the resident if they do pass away that somebody that was familiar to them is there’ (p145).

Place of care – home vs. out of home: all agreed that the ideal place of care was a person’s own home although they recognised this is not always possible. Staff in learning disability settings said they could support people in place up to a certain point and then physical barriers made it difficult, such as needing hoists and help with bathing. Nurses experienced in care for people with learning disability said that as long as there was adequate support, then it was preferable for people with dementia and learning disabilities to die in their own (community) home: ‘it has a huge impact unless you have staff that are actually qualified ... the last few days are very intense and I don’t know whether the community houses would actually be able to physically and emotionally manage ... in years to come if the proper supports were put in place maybe – if they had a team that was mobile that would be the ideal thing ...’cause ideally it would be nice for people to die at home’ (p145).

Peaceful end of life environment: everyone agreed about the importance of having a peaceful environment at the time of death. If this couldn’t be provided, then respondents felt this could be a reason to move people out of their usual place of residence although opinion was divided about whether a specialist dementia or palliative care setting was most appropriate. There was also debate as to whether a specialist unit for palliative care would be better than a palliative care section of a community setting. In some sites people were reported to be moving in and out of hospital towards the end of their life and neither staff nor families thought this was ideal.

Quality care and comfort: respondents described the importance of paying attention to the detail of providing a good death. For example, spending time with the person, playing music instead of having the TV on etc.

Spiritual care: staff in all sites said that spiritual care was really important, ‘... they need the time for both medical and spiritual care. You can see it in their eyes. At the very end you can see that fear ... petrified ...’ (p146). However some said they didn’t have the skills needed to give spiritual care.

Planning care – involving families: everyone recognised that families were often the legal decision-makers with regard to the end of life care planning/choices. However they differed in their views about family involvement. Some felt it was important to involve families early on to discuss possibilities around end of life care, especially staff from the palliative care service. Others felt they actually knew the individuals better than their own families do and that it was therefore difficult to put families in a position of making decisions about end of life care.

Coordination of care: when planning doesn’t take place, this results in reactive decision-making and stress. By contrast, 1 site was described as having a dedicated physician and dementia team and families who were active in dementia care and planning. According to 1 participant, the problem with learning disability services is the use of contract medical staff so they argued that learning disability nurses should take the lead in future planning to ensure continuity of care.

Working with hospitals: participants were frustrated that when people were transferred to acute hospitals, decisions were being made about end of life care without discussion with learning disability staff from their usual place of residence. They felt that acute hospital staff were poorly equipped to make these decisions because they lack experience and don’t know the individual.

Understanding dementia and palliative care: across all sites, the view was that staff needed training in dementia. Some from learning disability services said they had no experience of dementia. The same was true in the palliative care unit. They questioned how they were supposed to manage ‘wandering’ in the context of a hospice and said that perhaps the learning disability services needed support with palliative care so people could be supported in place at the end of life. Therefore a more collaborative approach would be welcomed: ‘... I think that is the way to go ... collaboration would be important ... where a service can consult with specialist palliative care services on symptom management in the later stages for example ...’ (p147).

Pain assessment and management: learning disability staff said they had a lack of knowledge around pain and symptom management. They were open to and welcoming of specific training in this area.

Maintaining adequate hydration and nutrition: this is complex in people living with advanced dementia. Participants were frustrated with inadequate end of life planning, shown especially keenly when people are transferred to acute hospitals, for example, ‘they end up with a PEG tube ... a few days before they die...it’s a big problem’ (p148). Some recalled that when they have looked after people with PEG feeding it’s resulted in a distressing, suboptimal death. Others said PEG feeding wasn’t a problem and they hadn’t had anyone with a PEG tube so the question of whether ‘to feed or not to feed’ hasn’t been an issue. Others said it was very distressing when families told them not to use a PEG so they were left with no guidelines other than a note in the person's chart saying 'stop all fluids and food'. Participants in specialist palliative care emphasised the complexity of this kind of decision-making and felt this wasn't necessarily recognised in learning disability services.

Resuscitation: across all sites it was felt that people with learning disabilities and dementia should die in their own home/usual place of residence. However, staff in group homes did not feel equipped to deal with the dying experience. So dying in the community is possible but as long as it's properly resourced.

Cultural differences: cultural differences were identified across sites. Some commented on difficulties experienced when decisions about a person and their care were not being made in their wider family context. Others stated that they have to learn and adapt to the person's culture and be open to other ways of doing things.

6. McLaughlin D, Barr O, McIlfatrick S et al. (2014b) Developing a best practice model for partnership practice between specialist palliative care and intellectual disability services: a mixed methods study. Palliative Medicine 28: 1213–21

Methods: Mixed methods, quantitative and qualitative

Data: Views and experiences

Country: Northern Ireland, UK

Outline

This mixed methods study, conducted in Northern Ireland, was considered to be of moderate relevance to the research question (+) and moderate methodological quality (+). The study aimed to develop a best practice model, which would guide and promote partnership practice between specialist palliative care and intellectual disability services. A questionnaire survey among 47/66 services and interviews with 30 practitioners were conducted.

Findings

Equity of access to end of life care for people with learning disabilities: both survey and interview data showed that services and practitioners felt that people with learning disabilities were ‘marginalised’ and the equity of access to end of life care for people with learning disabilities was limited. They felt the person with learning disabilities should have the option to die in their familiar place of care.

Joint working and learning: the benefits and values of joint working and learning were highlighted as key and fundamental between these services, including GPs. It was felt that this partnership would help to dispel distrust, improve communication and end isolation between services. It would also help practitioners to gain confidence in dealing and coping with issues of death and dying, bereavement care, carer support and decision-making when providing end of life care for people with learning disabilities. Partnership and joint working also enabled understanding of each other’s roles, sharing information to facilitate referral/assessment through better coordination and supporting and empowering each other to provide good care and continuity of care.

Education and training needs: the need for focus training such as ‘regional meetings’, and joint ‘study days’ was identified to be important and relevant to improve end of life care and management for people with learning disabilities.

Based on these findings, the authors developed a framework for partnership practice between both the specialist palliative care and intellectual disability services, which they argue could have international applicability.

Considerations: this qualitative study was considered to be of moderate relevance to the research question (+) and moderate in terms of methodological quality (+). It was not clear whether the people being looked after by the specialist palliative services were ‘older’ so the Guideline Committee should be mindful of this in considering whether to apply the findings to our guideline population. View and experiences data also relied on retrospective accounts, which would make recall bias likely. The methodological shortcomings need to be considered when interpreting the generalisability and applicability of the findings to the end of life care of older people with learning disabilities.

7. Morton-Nance S, Schafer T (2012) End of life care for people with a learning disability. Nursing Standard 27: 40–7

Methods: Qualitative

Data: Views and experiences

Country: Essex, UK

Outline

This qualitative study, conducted in the UK, was considered to be of moderate relevance to the research question (+) and moderate in terms of methodological quality (+). The study aimed to explore the experiences of 6 district nurses caring for people with a learning disability at the end of their lives. Qualitative data were collected via interviews.

Findings

Person-centred end of life care: community nurses reported positive experiences when palliative care was person-centred and involved good planning, preparation and sharing of information with other healthcare professionals.

Barriers to quality care – access to end of life care: they found that the main barriers to improving quality of care included the difficulty for people with learning disabilities in accessing palliative care; experience of poor and undignified deaths because of the apathetic attitude toward people with a learning disability; and adopting a reactive rather than proactive approach to end of life care.

Barriers to quality care – communication: difficulties in communication between healthcare professionals and a failure to share important information; health professionals' inexperience and lack of understanding, skills and training, making it difficult to meet patients' basic needs.

Training and collaborative working: community nurses identified the need to raise awareness and provide training in palliative care at all levels and emphasised the importance of effective collaborative working and sharing of expertise across disciplines.

8. Ryan K, McEvoy J, Guerin S et al. (2010) An exploration of the experience, confidence and attitudes of staff to the provision of palliative care to people with intellectual disabilities. Palliative Medicine 24(6) 556–72

Method: Mixed methods

Data: Views and experiences

Country: Republic of Ireland

Outline

This is a mixed methods study using survey and focus group methodology to understand the experience, confidence and attitudes of staff to the provision of palliative care for people with learning disabilities. The study was conducted in the Republic of Ireland, with staff drawn from the population of 1 Health Service Executive area. Staff from learning disability and palliative care services completed surveys and participated in focus group discussions. A total of 389 questionnaires were distributed and 16 focus groups were held. The quality of the methodology was judged to be moderate (+) and the study had moderate relevance to the review question.

Findings

Surveys: 389 questionnaires were distributed and 261 were returned (67% response rate).

Level of importance placed on the provision of end of life care by learning disability staff: using a visual analogue scale (with 0mm being ‘not at all important’ and 100mm being ‘very important’) respondents were asked to define how important they felt it was for their organisation to provide good end of life care for service users. They rated its importance extremely highly by giving it a mean score of 95.99 (n=201, sd=8.04). There were no significant differences in opinion between all 4 major staff groups.

Level of staff experience in the care of people with learning disabilities towards the end of life: palliative care staff had a low level of experience in caring for people with learning disabilities. A total of 59% had provided care to a person with learning disabilities towards the end of life. However 63% had not cared for any individual with learning disability in the last year and 19.6% had cared for only 1 individual.

The number of learning disability staff who had cared for a service user towards the end of life was 136 (67.3%), so the overall experience of learning disability staff in providing care was greater than that of palliative care staff. In terms of frequency, in the last year, 59.5% of learning disability staff had cared for at least 1 person with intellectual disability at the end of life and in general, learning disability staff thought they would have to care for more people at the of life in future.

Assessment of confidence levels of staff in managing pain, symptom control and communication issues involving people with learning disabilities towards the end of life: using a visual analogue scale (with 0mm being ‘not at all confident’ and 100mm being ‘very confident’) respondents were asked to rate their confidence levels in a variety of situations. Palliative care staff were highly confident of their ability to provide palliative care to the general population (mean confidence level, 86.85) but only moderately confident of their abilities when caring for people with intellectual disabilities (mean confidence level 63.47 with the difference being significant).

Confidence levels of palliative care staff in relation to other areas – ability to manage pain/symptom control issues for general population, 81.86 (n=44, sd=18.24). Ability to manage pain/symptom control issues for people with learning disabilities, 54.38 (n=45, sd=28.43). Ability to manage communication issues for general population, 84.32 (n=53, sd=13.64). Ability to manage communication issues for people with learning disabilities 51.40 (n=52, sd=26.75).

Confidence levels of learning disability staff: confidence of learning disability staff in their ability to manage issues of pain/symptom control for people with learning disabilities but who do not have life-limiting illness, 68.92 (n=165, sd=31.88).

Confidence of learning disability staff in ability to manage issues of pain/symptom control for people with learning disability with life-limiting illness, 60.77 (n=165, sd=35.69).

Confidence of learning disability staff in ability to manage issues of communication for people with learning disability but who do not have life-limiting illness, 76.47 (n=170, sd=25.96).

Confidence of learning disability staff in ability to manage issues of communication for people with learning disabilities with life-limiting illness, 58.72 (n=183, sd=32.63) (both staff groups equally lack confidence in the areas of pain/symptom control and communication in the end of life care setting).

Focus groups: focus group findings seem to support the survey findings. Palliative care staff were willing to provide care to people with learning disabilities but were restricted in doing so due to their lack of knowledge. They said it was 'different' and more 'difficult' to provide end of life care to people with learning disabilities and they doubted their own ability to meet people's needs '... You do the best you can within the situation, and you hope that its appropriate to the situation' (focus group 1; R3: 783–4) (p570).

Similarly, although learning disability staff had a breadth of experience of supporting people with learning disabilities their training to date had not prepared them for caring for people with learning disabilities at the end of life: 'I remember, you know, when I was training it was – I can even see the section in the book – it was like, maybe two pages … "Care of the Dying Patient" … two pages … and "Preparing the Body". I'm like, 'Oh my God! Is this what I've to do?' But that was it. There was no such thing … I don't remember the buzz-word of "palliative care" at the time …' (focus group 11; R1: 336–40) (p570).

Palliative care staff said they felt dependent on learning disability staff or carers and would follow their lead in the management of the person's end of life care. All staff recognised that problems could be overcome if they worked in partnership but there was no evidence that collaboration happened and instead they persisted with their own in-house solutions.

Finally, the findings indicate that experience has a positive impact on confidence but staff were providing end of life care for people with learning disabilities so infrequently that they were unable to retain the skills they had learned or translate them into organisation wide knowledge.

9. Todd S (2013) 'Being there': the experiences of staff in dealing with matters of dying and death in services for people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 26: 215–30

Methods: Qualitative

Data: Views and experiences

Country: Wales, UK

Outline

This study, conducted in Wales, was considered to be of moderate relevance to the research question (+) and moderate in terms of methodological quality (+). The study aimed to develop an understanding of how staff interpreted and responded to the death of a person with intellectual disability and the values that shaped their accounts of these. Qualitative data were collected using semi-structured interviews with 22 staff working in learning disability residential services where a resident had died. They gave personal accounts of their experiences of staff in dealing with issues of death and dying.

Findings

Acceptance of death: staff accepted that the death of their clients was an important part of their work and death should not mean the end of their relationship and commitment to the deceased individuals. They felt that the residential homes were an appropriate place of death for people with learning disabilities under their care.

‘Being there’: ‘being there’ through the transition from living to dying and to being remembered was perceived by the staff to be important, a reflection of their personal and human values. ‘Good deaths’ were deaths that allowed staff to express ‘being there’, despite the emotional pain and the impact of death of a resident on the staff, though this concept might create tensions with the dying individual’s immediate family.

Emotional demands: staff felt that the emotional dimensions of caring for people with learning disabilities while they are dying are often not recognised. Staff were willing to meet these demands and saw them as an important part of their work. However, they felt ill prepared and under-supported.

10. Tuffrey-Wijne I, Giatras N, Butler G et al. (2013) Developing guidelines for disclosure or non-disclosure of bad news around life-limiting illness and death

to people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 26: 231–42

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This qualitative study, conducted across the UK, was considered to be moderately relevant to the review question (+) and the study methods were judged to be good (++). It aimed to examine stakeholders’ preferences for and reasons about disclosure and non-disclosure of bad news to people with intellectual disabilities who had life-limiting illness. Data were collected using focus groups and interviews (telephone, face-to-face, one-to-one, online). Study participants included people with learning disabilities (n=21), family carers (n=28), 26 specialist intellectual disabilities professionals (n=26), and general health professionals (n=34). Interviews with people with learning disabilities were supported through the use of storytelling and role-play.

Findings

Non-disclosure of bad news: while the people with learning disabilities gave a mixed response, family carers felt strongly that they wanted to protect their son or daughter from the truth.

Disclosure of bad news: learning disability professionals were in favour of disclosing bad news. They felt that the person with learning disabilities had a right to know. Medical healthcare professionals felt that the person with learning disabilities should be told about their own ill-health and poor prognosis, but only if full disclosure was right for the particular individual, as this would help the individuals to cope and make plans.

Reasons for non-disclosure: the main reasons for supporting non-disclosure by family carers were to prevent distress, both for the person with learning disabilities and the bearer of bad news, who might lack the knowledge and understanding or were unable to accept the news themselves.

Conditions for and potential harm of disclosure: disclosure of bad news to people with learning disabilities and a life-limiting condition with poor prognosis would depend on the person's capacity to understand abstract concepts. Also, whether they had a sense of time and ability to comprehend, retain and balance the information presented by these complex issues. Because of these reasons, professionals felt that disclosure could therefore be potentially harmful because it could result in distress and confusion. The authors suggested that an assessment of 'What parts of the truth should the person be helped to understand, and when?' was therefore important. This would involve agreeing how information should be given, taking into consideration the issues of the person's right to information.

Economics

No cost-effectiveness studies were identified and no additional economic analysis was undertaken for this review question.

Evidence statements

The evidence statements listed in this section synthesise the key themes across included studies.

EL1	There is a small amount of evidence that older people with learning disabilities want equal access to end of life care services, including access to support and comprehensive information about their condition. The quality of the evidence is moderate. McLaughlin (2014a +) found that people with learning disabilities and their family carers expressed a need to improve access to and be given information about end of life care services.
EL2	There is some evidence that, according to health practitioners, equity of access to end of life care for people with learning disabilities is limited. The quality of the evidence is moderate. McLaughlin (2014b +) found that people with learning disabilities were 'marginalised' with poor access to end of life care services. Morton-Nance (2012 +) found that 1 of the main barriers to improving quality of care was the difficulty for people with learning disabilities in accessing palliative care.
EL3	There is a small amount of evidence based on views and experiences data that end of life care would be improved if professionals worked more closely with family carers and people with learning disabilities. The quality of the evidence is moderate. In the UK study by McLaughlin et al. (2014a +) people with learning disabilities and their family carers said that doctors, nurses and other professionals needed to work more closely with them and learn from them about ways of improving end of life care. They also emphasised the importance of a holistic family-centred approach in end of life care, with professionals working together with families to achieve this. In McCarron et al. (2010 +) disability service staff said that keeping links with family to maintain relationships was

	important, especially for people with learning disabilities and dementia throughout the continuum/progress of dementia.
EL4	There is a good amount of evidence, from views and experience studies, that better collaborative working between professionals would improve end of life care for people with learning disabilities. The quality of the evidence ranges from low to moderate. In Morton-Nance and Schafer (2012 +) district nurses emphasised the importance of effective collaborative working and sharing of expertise across disciplines to improve end of life services for people with learning disabilities. The nurses also said that difficulties in communication between healthcare professionals created barriers to good quality end of life care. McLaughlin et al. (2014b +) reported that specialist palliative services highlighted the benefits of joint working and learning between services as a way of generating trust, improving communication and ending isolation between services. In Bailey et al. (2016 -) community nurses emphasised the benefits of liaison between family and professional and nonprofessional carers, and collaborative working to promote the development of mutual understanding as to when and how to involve each other in the care process. This was seen as crucial for ensuring optimal end of life care for people with learning disabilities. Cross et al. (2012 -) highlighted problems when joint working does not occur: 'the project mostly involved direct health and social care professionals, trainers, and voluntary sector organisations, not system managers and not local users and family carers. This might explain some of the problems experienced in partnership working'. In McCarron et al. (2010 +) learning disability staff said they needed support with palliative care so that people could die in their home. Also, a more collaborative approach would be welcomed, where a service can consult with specialist palliative care services on pain management and symptoms. In Ryan et al. (2010 +) palliative care and learning disability staff said that any problems with end of life care could be overcome if they worked in partnership. However there was no evidence that this collaboration ever happened.
EL5	There is some evidence about the importance of person-centred care for people with learning disabilities at the end of their lives. The quality of the evidence is moderate. McCarron (2010 +) found that disability service staff felt that knowing the person's likes/dislikes were seen as being central to good dementia care. Respondents felt that learning disability services have a strong philosophy of person-centred care. Morton-Nance (2012 +) found that community nurses reported positive experiences when palliative care was person centred and included good planning, preparation, outreaching and sharing of information with other healthcare professionals. Cartlidge (2010 -) reported that staff felt it was very important to get to know people with learning disabilities and to build up trust and confidence when caring for them at the end of their lives.
EL6	There is some evidence that health professionals believe people with learning disabilities should be supported to die in their usual place of residence, not least because of the familiar and peaceful environment. The quality of the evidence is moderate. In McLaughlin et al. (2014b +) specialist palliative professionals said the person with learning disabilities should have the option to die in their familiar place of care. McCarron (2010 +) reported that most learning disability staff agreed the ideal place for end of life care was a person's own home although they recognised this is not always possible because staff sometimes lack specialist knowledge. In the Todd study (2013 +) residential staff felt that the residential home was the most appropriate place of death for the person with a learning disability.

EL7	There is a moderate amount of evidence that certain professionals (nurses and learning disability staff) felt they lack the knowledge, skills and confidence to manage end of life care for people with learning disabilities, in aspects such as resuscitation, pain and symptom management and communication. The quality of the evidence is moderate. In Bailey (2016 -) community nurses said their lack of knowledge, understanding, confidence, communication skills and resources were the main barriers preventing them providing end of life care to people with learning disabilities. According to Cartlidge (2010 -) hospice staff found it difficult to discuss patients' health status and treatment compliance issues with them. It was hard to make them understand their conditions and also difficult to gain valid consent. They said it was hard to get to know the patient and adjust communication to suit their individual needs. In McCarron et al. (2010 +) learning disability staff said they lacked knowledge and needed guidance around issues such as pain and symptom management, resuscitation and maintaining adequate hydration and nutrition. They were open to specific training in these areas. In Morton-Nance and Schafer (2012 +) community nurses identified a number of barriers to providing good quality end of life care for people with learning disabilities. These included health professionals' inexperience and lack of understanding, skills and training, which make it difficult to meet patients' basic needs. In Ryan et al (2010 +) palliative care staff said that although they were willing, they felt unable to provide end of life care to people with learning disabilities due to their own lack of knowledge. Similarly learning disability staff said their training about end of life care had been inadequate.
EL8	There is a moderate amount of evidence that in-service training and education in palliative care would improve the quality of support for people with learning disabilities at the end of life. The quality of the evidence is mixed, ranging from low to moderate. The majority of community nurses (65–75%) surveyed in Bailey et al. (2016 -) identified in-service education and workshops as a means to support their educational needs and suggested lectures and workshops (70%) as their preferred mode of delivery. Morton-Nance (2012 +) reported that community nurses wanted training in palliative care at all levels and emphasised the importance of effective collaborative working and sharing of expertise across disciplines. McLaughlin (2014b +) identified that the education and training needs of specialist palliative professionals, in the form of regional meetings, and joint 'study days', would be welcome and were felt to be a means of improving end of life care for people with learning disabilities. Cross (2012 -) found that home care staff made good use of the training sessions provided by the project. Learning disability community teams also benefited and were better informed about palliative care although views were mixed about whether it benefited palliative care professionals. The most appreciated aspects about the training were: reflecting on complex issues, thinking about difference, and facing fears.
EL9	There is a small amount of evidence that professionals believe a 'good death' means spending time with the person until the end. The quality of the evidence is moderate. McCarron et al. (2010 +) reported that learning disability staff described the importance of paying attention to the detail of providing a 'good death'. For example, spending time with the person, ensuring the person does not die alone. Todd (2013 +) found that residential staff perceived that 'being there' through the transition from living to dying and being able to remember the person after their death was important. 'Good deaths' were deaths that allowed staff to express 'being there', despite the emotional pain and impact of the death on staff.

EL10	There is a small amount of evidence that family carers of older people with learning disabilities need information and bereavement support, which is currently lacking. The quality of the evidence is moderate. In McLaughlin et al. (2014a +) family carers of people with learning disabilities who are at the end of their lives said they need bereavement support from a counsellor.
EL11	There is a small amount of evidence that health professionals perceived a need for support in coping with the emotional demands of end of life care. The quality of the evidence is moderate to low. Cross (2012 -) reported that the link worker scheme of the training project did not work well because link workers were not well supported by their organisations. Todd (2013 +) found that the emotional dimensions experienced by care staff in supporting people with learning disabilities was often not recognised, leaving them feeling ill prepared and under-supported.
EL12	There is a small amount of evidence about whether or not to give people with learning disabilities bad news about their illness or the estimated time they have to live. The evidence is mixed, highlighting conflicting views and the quality of the evidence is moderate. Tuffrey-Wijne (2013 +) reported that family carers supported non-disclosure in order to prevent distress, both for the person with learning disabilities and themselves as potential bearer of bad news. They were worried they might lack knowledge and understanding and may be struggling to accept the news themselves. Tuffrey-Wijne (2013 +) also found that medical health professionals thought disclosure could be potentially harmful because it could result in distress and confusion. This would particularly be the case if the person could not understand abstract concepts or a sense of time and could not comprehend, retain and balance the information. On the other hand Tuffrey-Wijne (2013 +) also reported that some medical healthcare professionals felt that the person with intellectual disabilities should be told about their own ill health and poor prognosis as this would help them to cope and make plans.
EL13	No evidence was found from studies published since 2005 about the effectiveness or cost-effectiveness of end of life care for older people with learning disabilities.

Included studies for these review questions

Bailey M, Doody O, Lyons R (2016) Surveying community-nursing support for persons with an intellectual disability and palliative care needs. British Journal of Learning Disabilities 44: 24–34

Cartlidge D, Read S (2010) Exploring the needs of hospice staff supporting people with an intellectual disability: a UK perspective. International Journal of Palliative Nursing 16: 93–8

Cross H, Cameron M, Marsh S et al. (2012) Practical approaches toward improving end-of-life care for people with intellectual disabilities: effectiveness and sustainability. Journal of Palliative Medicine 15 (3) 322–6

McCarron M, McCallion P, Fahey-McCarthy E et al. (2010) Staff perceptions of essential prerequisites underpinning end-of-life care for persons with intellectual disability and advanced dementia. Journal of Policy and Practice in Intellectual Disabilities 7: 143–52

McLaughlin D, Barr O, McIlfatrick S et al. (2014a) Service user perspectives on palliative care education for health and social care professionals supporting people with learning disabilities. BMJ Supportive & Palliative Care 5: 531–7

McLaughlin D, Barr O, McIlfatrick S et al. (2014b) Developing a best practice model for partnership practice between specialist palliative care and intellectual disability services: a mixed methods study. Palliative Medicine 28: 1213–21

Morton-Nance S, Schafer T (2012) End of life care for people with a learning disability. Nursing Standard 27: 40–7

Ryan K, McEvoy J, Guerin S et al. (2010) An exploration of the experience, confidence and attitudes of staff to the provision of palliative care to people with intellectual disabilities. Palliative Medicine 24(6): 556–72

Todd S (2013) ‘Being there’: the experiences of staff in dealing with matters of dying and death in services for people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 26: 215–30

Tuffrey-Wijne I, Giatras N, Butler G et al. (2013) Developing guidelines for disclosure or non-disclosure of bad news around life-limiting illness and death to people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 26: 231–42

3.8 Care and support in health settings

Introduction to review questions

Review question 9, comprised of parts a and b, is reported in this sub-section. Part a sought data about the self-reported views and experiences of older people with learning disabilities, their families, carers and advocates about care and support in health settings. Part b sought the views and experiences of people delivering, organising and commissioning social care, health and other services about care and support of older people with learning disabilities in health settings, including what works and what does not work well.

Review questions

9a. What are the views and experiences of older people with learning disabilities and their carers about care and support in health settings?

9b. What are the views and experiences of health, social care and other practitioners about the care and support of older people with learning disabilities in health settings?

Summary of the review protocol

The protocol sought to identify studies that would:

- Describe the self-reported views and experiences of adults, their families, carers and supporters about care and support in health settings, including what works and what does not work well.
- Describe the views and experiences of people delivering, organising and commissioning social care, health and housing services about care and support in health settings for older people with learning disabilities, including views on what works and what does not work well.

Population

Older people with learning disabilities and care and support needs, their families, supporters and carers.

Social care practitioners (providers, workers, managers, social workers), housing practitioners and health and social care commissioners involved in delivering care and support to older people with learning disabilities.

Intervention

Primary, secondary and community based health care provided to older people with learning disabilities.

Setting

Primary, secondary and community based health settings.

Outcomes

Person-focused outcomes (health and social care related quality of life; independence, choice and control over daily life; capability to achieve desired person-centred outcomes; user and carer satisfaction; speech, language and communication skills; continuity of care and years of life saved) and service outcomes (use of health and social care services; admission avoidance and need for support from care workers and carers). See 1.6 in the scope.

See Appendix A for full protocols.

Study design

The study designs relevant to this question included: systematic reviews of qualitative studies on this topic; qualitative studies of user, carer and practitioner views; qualitative components of effectiveness and mixed methods studies; observational and cross-sectional survey studies of user and carer experience.

See Appendix A for full protocols.

How the literature was searched

One single search was conducted for all but 1 of the review questions (RQ 8: End of life care). Electronic databases in the research fields of health (including mental health), social care, social science and economics were searched using a range of controlled indexing and free-text search terms. Additional searches of websites of relevant organisations, and trials registries were undertaken to capture literature that may have been missed from the database searches. The search was based upon 2 concepts: a) older people, ageing and future planning, or aged care services; and b) intellectual or learning disabilities.

A wide range of search terms are used to find these 2 concepts. The search terms were developed from various methods. This included finding 52 items that related to the topic, and discovering relevant search terms.

See Appendix A for full details of the search.

How studies were selected

Search outputs (title and abstract only) were stored in EPPI Reviewer 4 – a software program developed for systematic review of large search outputs. Coding tools were applied and all papers were screened on title and abstract. Formal exclusion criteria were developed and applied to each item in the search output, as follows:

- Language (must be in English).
- Population. (For question 9a, must be about older people with learning disabilities, their families or supporters. Note that in line with the scope, a specific age limit will not be used to define older people so a flexible and pragmatic approach to screening on the target population will be taken. For question 9b, must be about social care practitioners involved in delivering care and support at home to older people with learning disabilities.)
- Intervention (must be about care and support in health settings for older people with learning disabilities).
- Setting (must be primary, secondary and community-based health settings).
- Country (must be UK or other OECD).
- Date (must not be published before 2005).
- Type of evidence (must be research).

Title and abstract of all research outputs were screened against these exclusion criteria. Those included at this stage were marked for relevance to specific review questions and retrieved as full texts.

Full texts were again reviewed for relevance and research design. A list of studies excluded on full text can be found in Appendix A, organised by exclusion criteria.

If still included, critical appraisal (against NICE tools) and data extraction (against a coding set developed to reflect the review questions) was carried out. The coding was all conducted within EPPI Reviewer 4, and formed the basis of the analysis and evidence tables. All processes were quality assured by double coding of queries, and of a random sample of 10%.

See Appendix B for full critical appraisal and findings tables.

Overview of evidence

In our initial screen (on title and abstract) we found 120 studies which appeared relevant to review question 9. We retrieved and then reviewed full texts and included a total of 4 papers. An additional paper (Northway et al. 2016 +) was subsequently located through the update search, making a total of 5 studies for review question 9. Practitioners, service user and family views were all represented. The evidence gave a useful insight into the experiences and preferences of older people with learning disabilities in relation to health assessments and interaction with practitioners. However there were gaps in evidence about the perspective of health practitioners, for example, hospital practitioners or GPs.

Narrative summary of the evidence

In this section, a narrative summary of each included study is provided, followed by a synthesis of the evidence, according to the key outcomes, themes or sub-groups in the form of evidence statements [p217]. The approach to synthesising evidence was informed by the PICO within the review protocol.

The following study provides data about the views and experiences of people with learning disabilities, families (9a) and practitioners (9b) in relation to care and support in health settings for older people with learning disabilities. No studies were located that only provided practitioner views.

1. Fender A, Marsden L, John MS (2007) What do older adults with Down's syndrome want from their doctor? A preliminary report. British Journal of Learning Disabilities 35: 19–22

Methods: Qualitative

Data: Views and experiences

Country: UK, Scotland

Outline

The article reports a study, which aimed to find the best way of assessing the health of older people with learning disabilities. The quality of the study was rated as moderate (+) and it was judged to have good relevance (++) to our review question.

The study involved researchers working with Down’s syndrome Scotland to set up focus groups with 5 older adults. The characteristics of the participants are not given; we only know what all 5 had a learning disability. A total of 5 meetings were held and they were facilitated by a researcher. The topic for the first meeting was ‘What is health?’ but for the rest of the meetings, the older people themselves set the agendas. Members of the group helped to record the outcomes of the meetings.

Findings

The data collated via the focus groups provided information in 3 main areas: what health means to participants, what questions it is OK for doctors to ask older people with learning disabilities during assessments and what things it is OK for doctors to do during assessments?

In summary the study concluded that doctors need to be sensitive about asking personal health or social questions rather than about illness. ‘For example, it is fine for a doctor to ask how often someone goes to the toilet, but not the number of pairs of shoes they have’ (p21).

The group also made 4 suggestions for how to find out if a person is unwell and are unable or unwilling to tell you:

- Ask other people (ask whether something has happened to the person, for example whether they’re staying at home more, not wanting to go out or whether they’re not doing things they normally do or whether they’re crying a lot and blaming themselves).
- Look at the person (check whether they seem happy or are moving around as usual).
- Listen to the person (to see if they are in pain or are angry).
- Weigh the person.

More detailed findings about what doctors should and should not ask older people with learning disabilities and what should or should not happen in medical assessments are listed in the evidence tables.

2. Lalor A, Redmond R (2009) Breast screening for post-menopausal women. Learning Disability Practice 12: 28–33

Method: Survey

Data: Views and experiences

Country: Republic of Ireland

Outline

This study, conducted in the Republic of Ireland was judged to be of moderate quality (+) and had some relevance to the review question (+) particularly the section containing views about why breast examinations and mammography were not completed by older women with learning difficulties. The study aimed to identify practices around screening for women with learning difficulties and understand the reasons for nonattendance or non-completion of the procedure. The study analyses surveys completed by the primary carers of 129 post-menopausal women with learning disabilities. The study consisted of 24 questions and service users were given the opportunity to contribute if they were able. Most of the data was statistically analysed, no questions had an explicitly qualitative focus, but respondents were invited to contribute ‘other information’.

Findings

The study found that 2/3 of the 90 participants had successfully completed a mammography. This figure is lower than the national average.

Of those who attended, more than 3/4 completed the mammography. Those that completed are all classed as having a ‘mild’ disability. Those with a ‘moderate’ disability attended the appointment and 2/3 completed the procedure. Those with greater levels of disability had more issues with attendance and competition.

The perspectives of service users: most of those who did not finish their mammography, did not because of ‘a lack of cooperation’ (p31).

Other reasons were: ‘fear of the equipment, agitation, discomfort, dislike of physical touch, challenging behaviour, distress and a fear of the staff’ (p31).

Communication difficulties were found to be a reason for non-completion. All those who did not complete the procedure had some level of communication difficulties.

A quarter of the participants received clinical breast examinations. Of those who did not have a mammography, a quarter had clinical examinations. Less than a fifth of participants had both types of test and of those who did not attend mammography appointments, only a few were offered clinical examinations.

3. Truesdale-Kennedy M, Taggart L, McIlfatrick S (2011) Breast cancer knowledge among women with intellectual disabilities and their experiences of receiving breast mammography. Journal of Advanced Nursing 67: 1294–304

Methods: Qualitative

Data: Views and experiences

Country: UK, Northern Ireland

Outline

This is a small-scale qualitative study, using focus groups to investigate the views and experiences of women with learning disabilities in relation to breast screening and breast cancer awareness. The quality of the study was judged to be good (++) although it is just moderately relevant (+) to our review question and wider scope. The study was conducted in Northern Ireland and involved a total of 19 women aged 31–50 years (n=3) and 50–69 years (n=16). All of the women had undergone breast mammography in the last 12 months and resided in some form of residential setting in 3 health and social care trusts in Northern Ireland. The data were collected throughout 2009. The focus group discussions were recorded and transcribed. The data were subject to thematic analysis by more than 1 researcher and also checked with some of the focus group participants.

Findings

Results were organised under 4 main themes:

1. Women's understanding of breast cancer.

2. Women's experiences of breast mammography.

3. Perceived barriers to attendance.

4. Perceived solutions to barriers.

Overall, stress, anxiety and some discomfort were experienced before and during the examination but afterwards the women felt relieved and said it wasn’t as bad as they had thought it was going to be. They said it would help others to feel better about breast examinations if they were provided with accessible information, given clear explanations before the examination and were accompanied in the screening by family members.

4. Webber R, Bowers B, Bigby C (2010) Hospital experiences of older people with intellectual disability: responses of group home staff and family members. Journal of Intellectual and Developmental Disability 35: 155–64

Method: Qualitative

Data: Views and experiences

Country: Australia

Outline

This Australian study was judged to be of good quality (++) and it has good relevance to the review area (++). The study used qualitative interviews and ‘grounded dimensional theory’ to look at the hospital experiences of older people with learning difficulties. The study interviewed staff carers and family carers working with 17 group home residents. Interviews were repeated up to 4 times over a 2.5-year period. Fifty-five people were interviewed. In general carers were unhappy with the standard of care delivered in hospital.

Findings

Staff attitudes: carers said that they felt that staff were ‘generally uncomfortable with or indifferent to the needs of people with intellectual disability’ (p157); ‘…they don’t wash them. They don’t even brush their hair or clean their teeth. They don’t put their glasses on them’ (p157).

Interviews with carers found that staff did not acknowledge the needs of older people with learning difficulties. In some cases it was felt that additional treatment was not necessarily based on the person's disability: 'We had a guy here who recently broke his foot … I was told he was deemed unsuitable for rehabilitation …that was so far below anything that was a reasonable expectation' (disability staff) (p157).

Knowledge about learning difficulties: carers thought that hospital staff had inadequate experience or training in working with people with learning difficulties, 'I don't think they have an understanding of anything in the disability field, I don't think they're trained or given any information …' (p157).

Family and professional carers had concerns about eating, and self-care. There were comments that uneaten food went unchallenged by staff and reports that that continent people were not taken to the toilet, instead being given incontinence pads: 'they hadn't even changed him, he'd had an accident and even when he came back from hospital, his pyjamas were all dirty' (family) (p158).

Interviewees also criticised a lack of sensitivity among hospital staff toward people's need for predictable routines and also regular pain management, neglect of both was felt to lead to disruptive behaviour.

Hospital staff communication: a key concern among carers was a lack of, or inappropriate communication from hospital staff, such as talking to patients about treatment when they could not understand, or failing to describe treatment or diagnosis to them when they did have capacity to understand.

Another communication issue was that staff did not take the time to interact with patients. This led to misunderstanding and challenging behaviour: 'Many residents with intellectual disabilities were unable to tell hospital staff when they needed something, whether it was for relief from pain, a trip to the toilet, or simply to unwrap a sandwich' (p158).

Carers said that staff misinterpreted the needs of older people and did not listen to the advice of the carers who knew them well. This led to difficulties with treatment and challenging behaviour from the patient: 'She doesn't like being there, because people hurt her there and she doesn't understand why they're doing it, and you can't explain it to her' (p159).

Challenging behaviour was thought to have knock-on effects such as early discharge, even if staff did not have medical knowledge or the capacity to implement discharge plans: 'There were several reports of group home staff being pressured to take the resident home despite their inability to provide appropriate and 24-hour care' (p159).

Positive experiences: staff did report some positive experiences, such as:

- staff allowed extra time to accommodate the needs of older people with learning difficulties
- hospital workers adapted to the non-verbal need of patients
- clear discharge policies allowed for additional support in the group home.

Positive experiences all occurred in hospitals that had clear policy and guidance around caring for this group.

Carer strategies: carers revealed that they had developed strategies to minimise the stress of hospitalisation. Carers were able to keep older people engaged while in hospital, explain procedures and work with staff to make the hospital less frightening. They could help contain challenging behaviour. Some carers assisted with treatment: 'The nurse came and she tried to take blood from him and because he wriggled his hand … I held him so she could do it' (p160).

Carers developed written materials about the individual, to help hospital staff understand modes of communication, preferences and medications. 'We tell them how the person communicates, we tell them any ongoing health needs, we tell them you know their likes or dislikes. How they like to be toileted, how they eat, if they eat' (p160). Carers did say that they did not think that hospital staff read the information and this led to the distress of residents and misunderstandings.

Carers worked to developed partnering relationships with hospital staff, in order to communicate likes and dislikes and potential issues. Partnering required both giving and receiving information and involving carers in decision making was seen as particularly important.

Carers had to advocate to avoid problems like premature discharge. Carers described heated exchanges with hospital practitioners, and sometimes a failure to achieve the desired result.

In general the problems experienced by older people with learning difficulties took their toll on family carers and care staff. Staff had to stay for extended periods in the hospital. Family carers struggled to provide the support they felt was needed due to work commitments.

5. Northway R, Holland-Hart D, Jenkins R (2016) Meeting the health needs of older people with intellectual disabilities: exploring the experiences of residential social care staff. Health & Social Care in the Community 25(3) 923–31

Method: Qualitative

Data: Views and experiences (practitioners)

Country: UK

Outline

This Welsh study, of moderate quality (+), had good relevance to the review question (++). The study aimed to address a gap in knowledge about the role played by residential care staff, who are not required to have any specialist health training, in monitoring the changing healthcare needs of older people with learning disabilities, and advocating for them in healthcare contexts. The researchers conducted semi-structured interviews with 14 house managers, who are typically responsible for managing the staff teams of 1 or more supported living settings for older people with learning disabilities. The study does not provide information about the supported living settings that the participants manage. They are described as a purposive sample, meaning that they were specifically selected for interview by the researchers, although the selection criteria are not stated. The interviews were transcribed, and through a process of analysis 5 major themes emerged, 3 of which are reported in this paper.

Findings

1. The first major theme is ‘meeting health needs’. The study reported that residential staff encounter a range of health conditions among residents, most commonly (but not limited to) diabetes, infections, dementia and mental health problems.

Residential care workers are involved in recognising, monitoring and meeting health needs, and this includes promoting healthy lifestyles wherever possible. Examples were given of staff noticing changes in residents’ health needs, leading to checks by health professionals, and of staff monitoring for changes to people’s health, including watching for the side effects of medication.

Generally relationships with health professionals were positive, but there were some issues. Some GPs were reluctant to carry out annual health checks or to visit residents at home, and some hospital staff expected residential staff to provide 24 hour care to residents while they were in hospital, which could not be provided.

Keeping records of all health-related contacts was recognised as an important way of ensuring continuity of care and support when there are changes of care personnel, and some managers were trying to develop ‘health passports’ or ‘traffic light’ records that would accompany residents into hospital, providing important details about care and support needs. However, hospital staff did not always pay attention to this information.

2. The second major theme was ‘the consequences of ageing’. Residents could need more support and more time as a result of signs of ageing, such as cognitive decline, sensory loss, mobility problems and becoming generally slower. Participants were willing to support residents ageing in place, giving residents’ right to stay in their own home as a reason for supporting this, as well as the difficulty of finding suitable alternative placements. However, due to the increasing costs of caring for less able people, as well as the impact on staff and other residents, there would come a point where it became necessary to move people on. Participants could sometimes help residents age in place by recognising the need for environmental adaptations, for example, a walk-in shower or different height toilet.

Some participants spoke about providing end of life care, even where this amounted to nursing care.

3. The third major theme was 'relationships', which was seen as key to meeting residents' needs. Knowing the person helped staff and health professionals to be sensitive to any health changes in residents, and provided a basis for effective working. However, appropriate boundaries within these relationships were important for protecting both staff and residents. Participants also felt that when they formed a positive relationship with health professionals it had a positive impact on the way residents' health concerns were dealt with. However, some participants had encountered health professionals who did not understand or respect the roles of residential staff.

The study concluded that 'there is an urgent need for greater planning for this client group to ensure that appropriate services are available when needed: changes are needed to both policy and practice' (p7).

Economics

The review question did not include considerations of cost-effectiveness.

Evidence statements

The evidence statements listed in this section synthesise the key themes across included studies.

HS1	There is a small amount of evidence that health practitioners do not communicate well with older people with learning disabilities, resulting in poor health care experiences. One study (Webber et al. 2010 ++) reported a particular concern among carers was a lack of or inappropriate communication from hospital staff, e.g. when talking to patients about treatment they could not understand. Practitioners also failed to take time to interact with older people with learning disabilities. This could lead to misunderstandings (p8). Another study (Fender et al. 2007 ++) reported that older people with learning disabilities agreed that doctors should be sensitive about the questions they ask people during examinations. They also recommended ways that doctors can diagnose problems when a person is unable to communicate (p3).
HS2	There is a small amount of evidence that health practitioners lack understanding about the needs of older people with learning disabilities. The quality of the evidence is mixed, moderate to good. A good quality study by Webber (2010 ++) found, that in the experience of carers, hospital practitioners seemed uncomfortable and inexperienced with older people with learning disabilities. This resulted in unmet personal care needs and poor communication. It also led to a lack of sensitivity about the importance of following people's personal routines and pain management plans. This lead to disruptive behaviour. In the worst cases, carers felt that this lack of understanding resulted in premature transfer from hospital and pressure on group homes to accept the resident following discharge (p8). Northway et al. (2016 +) found that when health

	practitioners respected the special insight that managers of supported living schemes have into residents' changing health needs, this provides a basis for effective joint working to address those needs.
HS3	There is a small amount of evidence that breast screening is a frightening experience for women with learning disabilities. The quality of the evidence is moderate to good. A good quality study by Truesdale-Kennedy et al. (2011 ++) found that women with learning disabilities were stressed and anxious before and during a breast screen and afterwards felt relieved (p6). A moderate quality study (Lalor and Redmond 2009 +) found that older women with learning disabilities did not complete their examinations due to fear of the equipment and of staff, resulting in agitation and challenging behaviour (p4).
HS4	There is a small amount of evidence that people's experiences of health check-ups or assessments are markedly improved when they are given clear explanations about what to expect. The quality of the evidence is good. A study by Truesdale-Kennedy et al. (2011 ++) reported that women with learning disabilities felt that breast screening would be far less frightening if they were provided with accessible information and given clear explanations about what to expect before the examination (p6). A study by Webber (2010 ++) found that carers were concerned about the failure of hospital practitioners to describe treatment and diagnosis to older people with learning disabilities on the assumption that they would not understand (p8).
HS5	There is a small amount of evidence that family carers or advocates of older people with learning disabilities should be present during a hospital stay or medical appointment. The evidence is mainly good quality. A study by Webber et al (2010 ++) found that being present during hospital treatment meant carers could explain the person's needs, preferences and modes of communication. They could also assist with treatment, help reduce behaviour that challenges and in some cases, advocate to prevent premature transfer from hospital (p8). A study by Truesdale-Kennedy et al. (2011 ++) reported that women with learning disabilities felt breast screening would be less frightening if family members could accompany them (p6).

Included studies for these review questions

Fender A, Marsden L, John MS (2007) What do older adults with Down's syndrome want from their doctor? A preliminary report. British Journal of Learning Disabilities 35: 19–22

Lalor A and Redmond R (2009) Breast screening for post-menopausal women. Learning Disability Practice 12: 28–33

Northway R, Holland-Hart D, Jenkins R (2016) Meeting the health needs of older people with intellectual disabilities: exploring the experiences of residential social care staff. Health & Social Care in the Community 25(3): 923–31

Truesdale-Kennedy M, Taggart L, McIlfatrick S (2011) Breast cancer knowledge among women with intellectual disabilities and their experiences of receiving breast mammography. Journal of Advanced Nursing 67: 1294–304

Webber R, Bowers B, Bigby C (2010) Hospital experiences of older people with intellectual disability: responses of group home staff and family members. Journal of Intellectual and Developmental Disability 35: 155–64

3.9 Evidence to recommendations

This section of the guideline details the links between the guideline recommendations, the evidence reviews, expert witness testimony and the Guideline Committee discussions. Section 3.9 provides a summary of the evidence sources for each recommendation. Section 3.10 provides substantive detail on the evidence for each recommendation, presented in a series of linking evidence to recommendations (LETR tables).

Summary map of recommendations to sources of evidence

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
Access to services and person-centred care	
1.1.1 Ensure older people with learning disabilities have the same access to care and support as everyone else, based on their needs and irrespective of: • age • disability • gender reassignment • marriage and civil partnership • pregnancy and maternity • race, religion and belief • sex and sexual orientation • socioeconomic status • other aspects of their identity. [This recommendation is adapted from the NICE guideline on service user experience in adult mental health.]	GC consensus

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
1.1.2 Give older people with learning disabilities care and support that is tailored to their needs, strengths and preferences and is not determined solely by their age or learning disability.	AR3
1.1.3 Service providers and commissioners must make reasonable adjustments to health, social care and housing services to ensure they are fully accessible to older people with learning disabilities and their family members and carers, in line with the Equality Act 2010.	AR2
1.1.4 Recognise that older people with learning disabilities may be carers, but may not see themselves as such. Ask the person if they have caring responsibilities and, if so, offer them a carer's assessment to meet their needs. [This recommendation is adapted from the NICE guideline on older people with social care needs and multiple long-term conditions.]	IAR6
Communication and decision-making	
1.1.5 Practitioners must support people's communication needs and information preferences in line with NHS England's Accessible Information Standard. This includes: • Finding out before an appointment how the person prefers to communicate and receive information. • Extending appointment times to give more time for discussion. • Giving people written information (such as appointment letters and reminders) in an accessible format of their choice, for example Easy Read, audio books, films or by using online resources such as specialist learning disability websites. • Providing information on advocacy services and, if the person needs it and consents to it, providing an independent advocate who will attend appointments. • Using visual aids and short, clear sentences during consultations and conversations. • Talking to the person's family members and carers, if appropriate and with the person's consent.	HS1; AR2

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
1.1.6 Give older people with learning disabilities and their family members and carers accessible information about: • the range and role of different health services (such as health checks and screening) • how to access health, social care and support services • the community and specialist services that are available, and their purpose • housing options that they could think about for the future.	AR5
1.1.7 Social care and primary care practitioners should regularly review the communication needs of people with learning disabilities as they grow older to find out if they have changed. This should usually be when: • other needs are being assessed, for example during general health and dental checks • there is reason to believe their communication needs may have changed.	HS1
Decision-making, mental capacity and consent	
1.1.8 Assume that older people with learning disabilities have mental capacity to participate in planning and decision-making about their care and support unless it is established that they lack capacity, in line with the Mental Capacity Act 2005. Assess the person's capacity for each decision and carry out this assessment where and with whom the person wishes.	IAR6
Involving people and their family members and carers	
1.1.9 Health and social care practitioners should listen to, actively involve and value key members of the person's support network in the planning and delivery of their current and future care and support, if the person agrees to this. Regularly check people's willingness and ability to be involved in this way.	AR5; FCA1
1.1.10 Ask the person who they want to involve if they do not have close family members. Ensure they are aware of their right to an advocate and how to access this support.	IAR6
1.1.11 Find out and prioritise the needs and preferences of the person. Ensure these are not	AR5

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
overshadowed by the decisions or preferences of others, including when the person lacks capacity.	
1.1.12 Be aware that older people with learning disabilities may need support to communicate their needs or retain information. With the person's consent, share information with their family members and carers, including about: • any changes that might be needed to their care and support • symptoms, management and prognosis of the person's health conditions.	HS1; IAT1
Planning and commissioning local services	
1.2.1 Health and social care commissioners should have an understanding of the needs of older people with learning disabilities in their area and know what mainstream and specialist services are available locally to support people as they grow older.	AR3
1.2.2 Commissioners should identify the number of households that include an adult with a learning disability, and use this information to identify gaps in provision, organise services and plan future provision. This could be done by encouraging GPs to develop and maintain registers of people with learning disabilities and getting information from other support services, including education and the Department for Work and Pensions.	H7
1.2.3 Commissioners and service providers should ensure family members, carers and advocates of older people with learning disabilities have age-appropriate community support services and resources such as: • day opportunities • short respite breaks (both at home and away from home) • family placements • support groups for family carers, including siblings, and for older people with learning disabilities who have caring responsibilities • a single point of contact for practical information, emotional support and signposting.	FCA3
1.2.4 Commissioners and service providers should provide housing options that meet the	IAR1; H5

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
changing needs of people with learning disabilities as they grow older. This includes: • making reasonable adjustments to accommodate their changing physical and emotional needs • providing equipment or housing adaptations • ensuring accessible transport links are available to help people access local facilities • arranging housing for older people with learning disabilities who are in unstable housing situations, for example those who are homeless or in temporary accommodation (including people seeking asylum).	
1.2.5 Commissioners should make available locally a wide range of housing, family and community support options to meet the needs of older people with learning disabilities, as they grow older, including people in later old age and their family members and carers. These might include: • access to advocacy services • respite care • in-home support (such as physical adaptations) • supported living • residential and nursing care which reflect gender, sexual orientation and cultural preferences.	IAR6
1.2.6 Consider the use of telehealth and telecare for older people with learning disabilities, their family members and carers, and relevant partners such as GPs and adult social care services.	H4
1.2.7 Clinical commissioning groups should identify where there are gaps in community optometry and dental services for older people with learning disabilities and address those gaps.	AR1
1.2.8 Mental health commissioners should develop protocols to ensure that older people with learning disabilities, including people in later old age, have access to mainstream mental health	AR3

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
services for older people, including dementia support.	
1.2.9 Commissioners and service providers should ensure that older people with learning disabilities have equal access to a range of community services that reflect the cultural diversity of the local area and people's hopes, preferences, choices and abilities as they grow older.	R5; R8
1.2.10 Commissioners and providers should establish links between specialist learning disability services and mainstream older people's services. This could be done by bringing them together to help identify gaps and inform service development, sharing information and learning, and linking into voluntary sector umbrella groups.	IAT6
1.2.11 Commissioners and providers should provide opportunities for older people with learning disabilities to meet up and socialise, for instance through social clubs and support groups.	R7
1.2.12 Commissioners and providers should ensure there is a wide range of community-based physical activity programmes available and encourage people to take part to promote their health and wellbeing. Examples include dancing, swimming, bowls, using the gym, organised walks and chair-based exercise classes.	R7
1.2.13 Commissioners and providers should arrange accessible opportunities for older people with learning disabilities to engage in education, working and volunteering.	R4
1.2.14 Local authorities should consider introducing schemes to make transport easier for older people with learning disabilities. For example: • providing free travel such as London's 'Freedom pass' • using minibuses as community transport • starting 'buddy' schemes to enable independent travel • developing transport especially for people living in rural locations • schemes such as 'JAM' cards (Just A Minute) – which can be used to alert	R2

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
transport staff that people have a learning disability - schemes to help people with a personal budget to travel to activities and self-advocacy groups.	
Assessing people’s need for care and support	
1.3.1 Ensure that all assessments of care and support needs are person centred (NICE is publishing a guideline on people's experience in adult social care services in February 2018 which covers person-centred assessment).	IAR2
1.3.2 Practitioners carrying out assessments of care and support needs should have: - access to the person’s full history (medical, social, psychological and the nature of their learning disability) and - an understanding of their usual behaviour.	IAR2
1.3.3 Practitioners carrying out assessments of care and support needs should be alert to any changes in the person’s usual behaviour. This could include how they are communicating or their activity levels, and symptoms (such as weight loss, changes in sleeping patterns or low mood) that could show something is wrong or they are unwell.	IAR2
1.3.4 When people have changing needs think about whether these changes could be age-related and do not assume they are due to the person’s learning disability.	IAR2
1.3.5 Practitioners conducting assessments of care and support needs should help people to think about what they want from life as they age. This should include: - asking people how they would like to spend their time and with whom - encouraging them to develop support networks and to build and maintain links with friends and family and with community groups – these might include social, cultural and faith-based groups.	R1; R6
Assessing the needs of family members and carers	
1.3.6 Practitioners conducting assessments of care and support needs should take into account the needs, capabilities and wishes of families and carers. Also take into account that there may be mutual caring between older people with learning	IAR4

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
disabilities, and their family members and carers, who are likely to be older themselves, and have their own support needs.	
1.3.7 Practitioners must offer people who are caring for an older person with a learning disability their own carer's assessment, in line with the Care Act 2014.	IAR4
1.3.8 Based on assessment, provide families and carers with support that meets their needs as carers.	IAR4
1.3.9 Review the needs and circumstances of carers at least once a year and if something significant changes.	FCA3
1.3.10 Actively encourage carers to register themselves as a carer, for example with their GP.	IAR4
Person-centred planning and review	
1.4.1 Practitioners should carry out regular person-centred planning with people who have a learning disability to address their changing needs, wants and capabilities. This includes planning for the future. Involve their family, carers and advocates as appropriate.	HS4
1.4.2 Include transport needs in people's care and support plans, to help them get to services, appointments and activities.	AR3
1.4.3 Local authorities should plan people's care and support in a way that meets the needs of all family members, as well as the older person with a learning disability. This might include combining the personal budgets of different family members.	Expert witness testimony
1.4.4 Give families and carers, including siblings, help in planning and providing support for the older person with a learning disability. For example, signposting people to resources about how to support people after a family bereavement.	FCA1
Planning for the future	
1.4.5 Health and social care practitioners should work with the person and those most involved in their support to agree a plan for the person's future. Help them to make decisions before a crisis point or life-changing event is reached (for example, the death of a parent or a move to new housing).	IAR5
1.4.6 Planning for the future should:	IAR3; FCA1; IAR6; IAR4

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
- be proactive - be led by the person themselves with input from family members, carers and advocates as appropriate (regardless of whether they provide care and support themselves) - involve a practitioner who has a good relationship with the person and communicates well with them - involve practitioners who have good knowledge of local resources. - take into account the whole of the person's life, including their hopes and dreams as well as the things they do not want to happen - include considering the needs of family members and carers - seek to maintain the person's current support and housing arrangements, if this is their preference - be reviewed every year and whenever the person's needs or circumstances change.	
1.4.7 Include as key components of a future plan: - Housing needs and potential solutions. - Any home adaptations or technology that may address people's changing needs as they grow older. - Members of the person's support network (both paid and unpaid). - Any help the person gives to other family members, whether this will continue as they age, and the impact this may have on their health and wellbeing. - Financial and legal issues, for example whether someone has been appointed to have lasting power of attorney for the person. - Planning for unexpected changes or emergencies. - Consideration of deprivation of liberty safeguards, for instance if planned changes to care or the care environment	IAR3; EL5

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
are likely to increase restrictions on the person. • End of life care decisions – including where the person wants to be when they die. These decisions should be reviewed at least once a year.	
Future planning for housing	
1.4.8 When helping the person plan where they will live in the future and who they will live with, take into account whether other family members rely on them for support.	IAR6
1.4.9 Encourage and support people to be active and independent at home regardless of their age or disability. This might include doing household tasks, making their own decisions and plans or leading group activities.	R4
1.4.10 Make reasonable adjustments to people's homes as they grow older to make it possible for them to stay in their current home if they want to. For example, consider a support phone line, daily living equipment, telehealth monitoring and home adaptations, such as shower room conversion, wider doorways or a lift between floors.	H6
1.4.11 Review the housing needs of people who are being supported by social care staff at home at least once a year.	H6
1.4.12 Ensure that an advocate or, if appropriate, a family member or carer is centrally involved in decisions about whether a person should move from supported living to residential care.	H6
1.4.13 If a move into residential care is agreed with the person, practitioners should work with them and their support network to start planning for this straightaway. Planning could include: • arranging for the person to visit the residential setting • discussing how they will maintain their existing support networks and develop new ones.	IAR1
Identifying and managing health needs	
1.5.1 Healthcare practitioners should encourage older people with learning disabilities to choose a family member or carer to bring with them to medical examinations and appointments if they would like this support.	HS3; HS5
1.5.2 Explain clearly to older people with learning disabilities what will happen during any	AR4

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
medical appointments as well as their likely follow-up care. In line with the Mental Capacity Act 2005, healthcare practitioners must take all reasonable steps to help the person understand the explanation.	
1.5.3 If the person needs a medical examination give them a choice, wherever possible, about where it takes place. Aim to do it in a place that is familiar to them, which is welcoming and appropriate to their needs.	HS3
1.5.4 As well as explaining to people beforehand what will happen, continue to explain what is happening throughout the appointment and ensure there is enough time set aside to do this. If the person agrees, also explain to their family members and carers what will happen.	HS3
1.5.5 Support family members and carers, for example through the provision of information, to enable older people with learning disabilities to access health services.	AR5
1.5.6 Consider training for people and their family members and carers in recognising and managing age-related conditions such as: • hearing loss and sight problems • blood pressure and cholesterol • prostate cancer • epilepsy • diabetes • osteoporosis • thyroid problems • menopausal symptoms. • mental health, including depression and dementia.	FCA5
Co-ordinating care and sharing information	
1.5.7 Managers in healthcare settings should identify a single lead practitioner to be the point of contact for older people with learning disabilities and their family members and carers. This practitioner could be a member of the community learning disability team or a nurse with experience in learning disabilities.	HS3
1.5.8 Ensure that everyone involved in the person's care and support shares information and communicates regularly about the person's health and any treatment they are having, for example by	IAT3

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
holding regular multidisciplinary meetings. Involve the person in all discussions.	
1.5.9 Primary and secondary healthcare teams should identify at least 1 member of staff who develops specific knowledge and skills in working with older people with learning disabilities and acts as a champion, modelling and sharing good practice. Use the expertise of older people with learning disabilities to ensure the champion understands their needs.	HS2
1.5.10 Record a person's learning disability in their health records. With the person's consent, make sure all healthcare practitioners in community and acute settings can access this. Also record any specific needs or wishes, for example to do with the person's communication or mobility.	AR4
Health checks and screening	
1.5.11 Offer older people with learning disabilities the same routine screening and health checks as other older people.	IAR2
1.5.12 Recognise that older people with learning disabilities may need additional health surveillance to help them identify and communicate symptoms of age-related conditions. This could include providing information about annual health checks including what they involve and how to arrange them.	HS4
1.5.13 Discuss with people changes that may occur with age. Ask them about and monitor them for symptoms of common age-related conditions, including: • hearing loss and sight problems • blood pressure and cholesterol • prostate cancer • epilepsy • diabetes • osteoporosis • thyroid problems • menopausal symptoms. • mental health, including depression and dementia (also see recommendations 1.5.36 and 1.5.37).	HS2; FCA5
1.5.14 If the person is having an annual health check, give them information about other available	HS4

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
services, including a care and support assessment under the Care Act 2014 if they have not already had one.	
1.5.15 If the person is having an annual health check, ask if they are registered with a dentist, how often they see the dentist and check that they understand the importance of looking after their teeth and mouth.	AR1
1.5.16 Give people clear, accessible and practical information and advice about keeping well as they grow older. Tell them about, and help them to access, preventative services such as breast screening, smear tests, testicular and prostate checks and dental checks.	IAT2; AR2; IAT3; AR6
1.5.17 When designing and delivering breast screening services, address specific barriers to accessing breast screening among older women with learning disabilities, including support to: • understand breast cancer • understand the screening procedure • perform breast self-examination • understand any information provided • attend appointments.	AR6
Primary care	
1.5.18 Design primary care and community services so that older people with learning disabilities can see the same GP and other healthcare practitioners, wherever possible to help practitioners: • become familiar with the person's medical history, which the person may have difficulty remembering themselves • build good relationships and understand the person's usual behaviour and communication needs.	AR4
1.5.19 General practices should allocate a named member of staff to remind older people with learning disabilities about appointments for screening and health examinations. This staff member should help the person attend the appointment by:	AR2; AR6

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
• using each person's preferred method of communication • giving them information in a way they can understand • ensuring the person understands the reason for the appointment and why it is important • finding out their transport needs • making reasonable adjustments to help the person and their carer or supporter to attend.	
1.5.20 If the person is diagnosed with a health condition give them, and their family members and carers, accessible information on the following (taking time to explain it to them as well): • symptoms and management • benefits, and potential side effects, of treatment • how to take their prescribed medicines.	IAT1
1.5.21 Support older people to manage their own health conditions by getting to know them and adapting health advice to suit their personal choices and the activities they already enjoy (for example, playing football).	IAT2
Dental care	
1.5.22 Commissioners and managers should ensure support staff have knowledge of oral health so they can support older people with learning disabilities to maintain good oral health and access dental services.	AR1
1.5.23 Dental practices should ensure their services are accessible to older people with learning disabilities, for example by: • reminding people about their appointments by phone • sending letters in an accessible format, for example Easy Read • suggesting that the person brings a carer or supporter with them • ensuring staff have the skills to communicate with people with learning disabilities and put them at ease.	AR1

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
1.5.24 For further guidance on managing oral health see the NICE guidelines on: - oral health promotion: general dental practice - oral health for adults in care homes.	Other relevant NICE guidelines
Outpatient appointments	
1.5.25 Hospitals should arrange for the person and a family member or carer to visit the hospital before their outpatient appointment to meet the staff who will conduct any tests or examinations, see the equipment that will be used and identify what adjustments will be needed.	HS3
Before and during a hospital stay	
1.5.26 When planning a hospital admission, arrange a pre-admission planning meeting, including the hospital liaison team or liaison nurse, a representative of the community learning disability team, the person and their family members and carers. At this meeting: - complete the pre-admission documentation, which should include information from the person's hospital passport - discuss any reasonable adjustments needed, for example, arranging for the person to visit the hospital before their admission to meet the learning disability liaison nurse who will be their contact.	HS5
1.5.27 Hospitals should actively encourage staff to use pre-admission documents and flagging systems so that all relevant hospital staff know about the person's learning disability. At discharge, review how well this is working.	HS2; HS4
1.5.28 Hospitals should develop policies and guidance to enable someone chosen by the person to stay with them throughout their inpatient stay. This should include providing facilities for them to stay overnight.	HS5
1.5.29 Hospital staff should continue to offer health and personal care (toileting, washing, nutrition and hydration) to older people with learning disabilities even if they have a family member or carer there to support them.	HS5
1.5.30 For further guidance on planning admission and admitting adults with identified social care needs to hospital, see NICE's	NICE guideline: Transition between inpatient hospital settings and community or

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.	care home settings for adults with social care needs
Transfer of care from hospital	
1.5.31 Invite family members, carers or advocates to pre-discharge meetings, as well as the person themselves. (79, HS5)	HS5
1.5.32 If the discharge plan involves support from family members or carers, take into account their: • willingness and ability to provide support • circumstances, needs and aspirations • relationship with the person • need for respite. [This recommendation is adapted from the NICE guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.]	HS5
1.5.33 Give the person (and their family members and carers) an accessible copy of their discharge plan when they are discharged, and make sure their GP has a copy within 24 hours. Make sure everyone knows what will happen next in the person's care and support. (81, HS5, adapted from H2H, 1.5.6) [This recommendation is adapted from the NICE guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.]	HS5
1.5.34 After the person is discharged, the hospital learning disability liaison nurse, community learning disability teams and primary care practitioners should work together to provide ongoing support to the person to help them manage their health conditions.	GC consensus
1.5.35 For further guidance on discharging adults with identified social care needs from hospital, see NICE's guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.	NICE guideline: Transition between inpatient hospital settings and community or care home settings for adults with social care needs
Care and support for people living with dementia	
1.5.36 Explain at an early stage to older people with learning disabilities (particularly people with Down's syndrome) and their family members or carers about the link between learning disabilities and dementia. Explain the signs of dementia, how	FCA2

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
it usually progresses and what support is available. Give people: - printed information on dementia - opportunities for one-to-one discussion with a professional - advice on communication strategies for people with dementia.	
1.5.37 Commissioners should ensure information is provided to family members and carers of older people with learning disabilities who are being assessed for, or have been diagnosed with dementia. Consider also providing training. Information and training might cover: - types of dementia - how dementia might present in people with different learning disabilities - care pathways for different dementias - practical steps to manage daily life - communication skills - how to find further advice and ongoing support, including support groups and respite services.	FCA3; FCA5
Access to end of life care services	
1.6.1 Give older people with learning disabilities and their family members and carers accessible information about all the potential care options available for end of life care, including hospice services.	EL1
Making sure end of life care is person centred	
1.6.2 Practitioners providing end of life care should spend time getting to know the person to understand their needs. Get to know how they communicate, their cultural background, what they like and dislike, how they express pain, their health conditions and the medication they are taking. Be aware that this understanding will make it easier to identify when the person's health is deteriorating.	EL5
1.6.3 Identify who the person would like to involve in creating their end of life plan. Include the person themselves and everyone who supports them in discussions and planning.	EL9

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
1.6.4 Ask the person regularly who they would like to involve in discussions about their end of life plan, in case they change their mind. Do this every 6 months or more often if the person is close to the end of life.	EL9
1.6.5 Make it possible for the person to die where they wish. This might include adapting their home, working with other practitioners and advocates, and talking to other residents or family members about changes that could be made (for example, moving the person to a room on the ground floor).	EL5; EL6
Involving families and support networks	
1.6.6 During end of life care planning, talk to the person and their family members and carers to understand the person's wishes and any cultural needs at the end of the person's life.	EL5
1.6.7 When providing end of life care, learn from family members and carers about the person's needs and wishes, including those associated with faith and culture, nutrition, hydration and pain management. This is particularly important if the person is unable to communicate.	EL3
1.6.8 Learning disability providers delivering care at the end of life should work collaboratively and share information with other practitioners and services involved in the person's daily life.	EL4
1.6.9 Social care providers should work in partnership with healthcare providers to share knowledge about the person and to develop expertise for end of life care.	EL4
1.6.10 Provide training, information and support for family members and carers, for example in medication, pain, nutrition and hydration, to enable the person to die where they wish to.	EL6
1.6.11 Make sure that key people in the support network have the knowledge, confidence and understanding to communicate with the person about their illness and death. This includes discussion about symptoms, pain management and preferences about resuscitation.	EL7
1.6.12 Mainstream end of life care services should make reasonable adjustments to support the person, their family members, friends and carers and other people they live with throughout palliative and end of life care and bereavement.	EL10

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
1.6.13 For further guidance on end of life care see NICE's guideline on care of dying adults in the last days of life.	NICE guideline: Care of dying adults in the last days of life
Workforce skills and expertise	
1.7.1 Managers in health and social care services should ensure that staff in older people's services have the expertise to support older people with learning disabilities from a wide range of backgrounds.	IAR1
1.7.2 Managers in health and social care services should ensure that learning disability staff have the skills and understanding to support people's changing needs as they grow older. Provide this skilled support in all settings, including people's own homes.	IAR1
1.7.3 Managers in health and social care services should ensure that all staff working with older people with learning disabilities have skills and knowledge in: • communication methods, including non-verbal communication • building good relationships with people with learning disabilities and making them feel at ease • the physical and mental health needs of older people with learning disabilities, related to both their age and disability • common health conditions to which older people with learning disabilities are predisposed, for example the earlier onset of dementia, ensuring that they do not confuse these with the person's learning disability or another condition.	FCA2; HS1; HS2; IAT5
1.7.4 Managers in health and social care services should provide opportunities for learning disability staff and practitioners working with older people to share expertise with each other as part of their knowledge and skills development.	H2
1.7.5 Staff should know what local services are available (including housing options) so they can support older people with learning disabilities, families, carers and advocates to make informed choices about their care and support.	H2
Workforce skills and expertise for supporting end of life care	
1.7.6 Commissioners and providers of end of life care should recognise the complex needs of older	EL4; EL7

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
people with learning disabilities. They should provide ongoing training for staff to ensure they have the expertise to provide good-quality coordinated care, enabling people to die in their own home or another place of their choice. Training should include: • having discussions about resuscitation intentions • finding out and responding to cultural preferences • managing symptoms, pain and medication • nutrition and hydration • understanding communication preferences and being able to communicate – this might include using an augmentative communication system.	
1.7.7 Provide in-service training for learning disability and palliative care practitioners so they have the skills to support people at the end of life. This might include joint study days and training of professionals by people with learning disabilities and their family members and carers.	EL8

3.10 Evidence to recommendations

Topic/section heading	**Access to services and person-centred care**
Recommendations	1.1.1 Ensure older people with learning disabilities have the same access to care and support as everyone else, based on their needs and irrespective of: • age • disability • gender reassignment • marriage and civil partnership • pregnancy and maternity • race, religion and belief • sex and sexual orientation • socioeconomic status • other aspects of their identity. [This recommendation is adapted from the NICE guideline on service user experience in adult mental health.] 1.1.2 Give older people with learning disabilities care and support that is tailored to their needs, strengths and preferences and is not determined solely by their age or learning disability. 1.1.3 Service providers and commissioners must make reasonable adjustments to health, social care and housing services to ensure they are fully accessible to older people with learning disabilities and their family members and carers, in line with the Equality Act 2010. 1.1.4 Recognise that older people with learning disabilities may be carers, but may not see themselves as such. Ask the person if they have caring responsibilities and, if so, offer them a carer's assessment to meet their needs. For further information see NICE's guideline on Carers: provision of support for adult carers [This recommendation is adapted from the NICE guideline on older people with social care needs and multiple long-term conditions.]
Research recommendations	The Guideline Committee agreed the following research recommendation to address gaps in evidence about the identification of health conditions: Research recommendation 2 a) What is the effectiveness and cost-effectiveness of different ways of identifying age-related and other physical and mental health conditions, in older people with learning disabilities? b) What can mainstream and specialist health services do to facilitate early identification of health conditions in older people with learning disabilities? c) What can mainstream and specialist health services do to facilitate equal access to health services in older people with learning disabilities?

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Review questions	1. What are the views and experiences of older people with learning disabilities and their carers about how care and support needs are identified, assessed and reviewed? 2. What are the views and experiences of health, social care and other practitioners about how the health and social care needs of older people with learning disabilities and their carers are identified, assessed and reviewed? 5a) What is the acceptability, effectiveness and cost effectiveness of interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 5b) What are the views and experiences of older people with learning disabilities and their carers about interventions or approaches to improve access and referral to health, social care and housing support services? 5c) What are the views and experiences of health, social care and other practitioners about interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 9a) What are the views and experiences of older people with learning disabilities and their carers about care and support in health settings? 9b) What are the views and experiences of health, social care and other practitioners about the care and support of older people with learning disabilities in health settings?
Quality of evidence	Recommendation 1.1.1 is based on evidence from review question 9 about the care and support of older people with learning disabilities in health settings and due to there being some overlap with the NICE guideline on service user experience in adult mental health, the recommendation is adapted from that guideline. Overall, for question 9, 6 studies were located and they were moderate to good in terms of internal validity. Practitioner, service user and family views were all represented, providing useful insight into the experiences and preferences of older people with learning disabilities in relation to health assessments and interaction with practitioners although there were clear gaps in evidence about the perspective of health practitioners e.g. hospital practitioners or GPs. Recommendation 1.1.2 is also based on evidence from review area 9 and supported by evidence from review area 5 about access and referral to health, social care and housing services. The evidence located for review question 5 (n=7) was moderate to good in terms of internal validity and provided data on the views and experiences of older people with learning disabilities, their families and carers and also of practitioners. There was no effectiveness evidence and the views and experiences data focussed on barriers to access rather than means of improving access and referral. Recommendation 1.1.3 is also based on evidence from review question 5, with the quality of the evidence as described above. Recommendation 1.1.4 is based on evidence from review questions 1 and 2 about the identification, assessment and review

	of care and support needs among older people with learning disabilities. Due to the overlap with the NICE guideline on older people with social care needs and multiple long term conditions, the recommendation was adapted from that guideline. For question 1, there were 7 studies, which on average were moderate in terms of their internal validity. Only 1 study of moderate quality specifically answered question 2 and a further 4 studies provided data to answer both questions 1 and 2 because they reported practitioner views as well as views of older people with learning disabilities and their carers or families. There were gaps in the evidence about assessment and review of needs, with most of the data covering future planning. The gaps in the data led to discussions based on committee expertise, with crucial input from the experts by experience, including carers.
Economic considerations	There are likely to be resource implications linked to the recommendations, in particular 1.1.1 to 1.1.3, which the guideline committee took in to consideration when developing the recommendations. However, in some cases recommendations may be followed by changing attitudes and practice, which may not require additional costs. Where additional costs are required (e.g. for putting reasonable adjustments in place to increase access), there is also the possibility of return on investment linked to putting the right care in place at an earlier time thus preventing potentially negative impacts for the person and their family, which might also be more costly. However, the recommendations in this section refer to general principles of care and support for this population, and the resource impact could not be estimated without further details about the nature of adjustments and person-centred support. The recommendations that follow in the next sections specifically outline how principles should be implemented and thus economic considerations are picked up under those more specific recommendations.
Evidence statements – numbered evidence statements from which the recommendations were developed	HS4: There is a small amount of evidence that people's experiences of health check-ups or assessments are markedly improved when they are given clear explanations about what to expect. The quality of the evidence is good. A study by Truesdale-Kennedy et al. (2011 ++) reported that women with learning disabilities felt that breast screening would be far less frightening if they were provided with accessible information and given clear explanations about what to expect before the examination (p6). A study by Webber (2010 ++) found that carers were concerned about the failure of hospital practitioners to describe treatment and diagnosis to older people with learning disabilities on the assumption that they would not understand (p8). AR3: There is a moderate amount of evidence that older people with learning disabilities have limited access to support because of a lack of services designed specifically to address their needs and preferences. The quality of the evidence is mostly moderate. Wark et al. (2015 ++) found that in rural Australia, older people with learning disabilities had to travel very long distances from home in order to access specialist health services. In addition, where learning disability services were available locally, access

	was limited by having few, if any, options (p5). Benbow et al. (2011 +) reported that learning disability practitioners said psychiatry services for older people in the UK specifically exclude people with learning disabilities (p8). The US study by Coyle (2016 +) reported clear difficulties from a practitioner perspective around being able to provide resources and support to older people with learning disabilities. As a result staff admitted to not addressing the needs of the specific population in the provision of services although it was something they recognized they ought to in future (p9). Finally, a study conducted in Ireland (Dodd et al. 2009 +) found that one of the reasons older adults with learning disabilities did not access specialist learning disability services was that families judged that they were not appropriate to meet the person's needs (p12). (Recommendation 1.1.2) AR2: There is some evidence that older people with learning disabilities can lack understanding and awareness about the importance of health interventions and this can limit their access to services. The quality of this evidence is mainly moderate. Mac Giolla Phadraig et al. (2014 +) found that irregular dentist attenders made a choice not to access this service – sometimes out of fear – or because they were unaware of the importance of dental checks (p1). Dodd et al. (2009 +) found that one of the reasons older adults were not accessing specialist learning disability services was that individuals themselves did not want this support (p12). McIlfatrick et al (2011 ++) identified a lack of understanding about breast examinations and breast cancer among women with learning disabilities, which acted as a barrier to accessing breast screening services (p15). (Recommendation 1.1.3) IAR6: There is some evidence that planning for the future of older people with learning disabilities should involve the whole family, including the person themselves. A moderate quality study by Coyle et al (2014 +) highlighted the importance of future planning with regard to the sibling role. Siblings said they needed to plan for a situation in which their parents could no longer provide care. Where parents had made future plans, a moderate quality study (Dillenberger and McKerr 2011 +) reported that they involved transferring the family home and caring responsibilities to non-learning-disabled children. On the other hand parents interviewed in a good quality study (Hole et al. 2013 ++) said they did not want their other children to be "burdened" with caring for their sibling. The results of this study point to the importance of early planning that balances the needs and desires of ageing adults with learning disabilities and family members. Finally, Bowey and McGlaughlin (2005 +) found that in situations of 'mutual caring', adults with learning disabilities were reluctant to move away to shared accommodation out of concern for how their parents will cope. This highlights that the line between carer and cared for is often blurred and everyone's wishes and needs must be considered during future planning. (Recommendation 1.1.4)
Other considerations	Recommendation 1.1.1 was developed on the basis of general discussions about access to health services for older people with learning disabilities arising from the evidence. The GC agreed that in practice this is very poor. In particular the experts by

	experience described negative experiences resulting from poor access and therefore wished to develop a recommendation to address this inequality. Recommendation 1.1.2 is based on evidence that access to care and support services is problematic because established services are not tailored to the needs of older people with learning disabilities. Nevertheless in ensuring services respond to people's specific needs, the guideline committee was keen to ensure those needs were not assumed on the basis that they are 'older' or have a learning disability. The key is to be person centred and this was the intention behind 1.1.2. Recommendation 1.1.3 is based on evidence that older people with learning disabilities sometimes lack understanding about health services or about the need for screening and health checks and sometimes avoid attendance through misperceptions or fear. In considering how to overcome this, the committee agreed that service providers and commissioners should make reasonable adjustments to make services more accessible and that considering the Equality Act this is a 'must' recommendation. Recommendation 1.1.4 was developed on the basis of IAR6, which highlighted that as well as considering the needs of family carers, planning should take into account that older people with learning disabilities often also provide care, for example for their parents. The guideline committee wished to develop a recommendation to ensure that recognition is given to this through asking the person if they do care for others and offering them a carers assessment. Due to the overlap with the NICE guideline on older people with social care needs and multiple long term conditions, the recommendation was adapted from that guideline.

Topic/section heading	**Communicating and making information accessible**
Recommendations	1.1.5 Practitioners must support people's communication needs and information preferences in line with NHS England's Accessible Information Standard. This includes: • Finding out before an appointment how the person prefers to communicate and receive information. • Extending appointment times to give more time for discussion. • Giving people written information (such as appointment letters and reminders) in an accessible format of their choice, for example Easy Read, audio books, films or by

	using online resources such as specialist learning disability websites. • Providing information on advocacy services and, if the persons needs it and consents to it, providing an independent advocate who will attend appointments. • Using visual aids and short, clear sentences during consultations and conversations. • Talking to the person's family members and carers, if appropriate and with the person's consent. 1.1.6 Give older people with learning disabilities and their family members and carers accessible information about: • the range and role of different health services (such as health checks and screening) • how to access health, social care and support services • the community and specialist services that are available, and their purpose • housing options that they could think about for the future. 1.1.7 Social care and primary care practitioners should regularly review the communication needs of people with learning disabilities as they grow older to find out if they have changed. This should usually be when: • other needs are being assessed, for example during general health and dental checks • there is reason to believe their communication needs may have changed. **Decision making, mental capacity and consent** 1.1.8 Assume that older people with learning disabilities have mental capacity to participate in planning and decision-making about their care and support unless it is established that they lack capacity, in line with the Mental Capacity Act 2005. Assess the person's capacity for each decision and carry out this assessment where and with whom the person wishes.
Research recommendations	The Guideline Committee agreed the following research recommendation to address gaps in evidence about the identification of health conditions: Research recommendation 2 What is the effectiveness and cost effectiveness of different ways of identifying age-related and other physical and mental health conditions, in older people with learning disabilities? What can mainstream and specialist health services do to facilitate: - early identification of health conditions in older people with learning disabilities? - equal access to health services in older people with learning disabilities?

Review questions	1. What are the views and experiences of older people with learning disabilities and their carers about how care and support needs are identified, assessed and reviewed? 2. What are the views and experiences of health, social care and other practitioners about how the health and social care needs of older people with learning disabilities and their carers are identified, assessed and reviewed? 5a) What is the acceptability, effectiveness and cost effectiveness of interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 5b) What are the views and experiences of older people with learning disabilities and their carers about interventions or approaches to improve access and referral to health, social care and housing support services? 5c) What are the views and experiences of health, social care and other practitioners about interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 9 a) What are the views and experiences of older people with learning disabilities and their carers about care and support in health settings? 9b) What are the views and experiences of health, social care and other practitioners about the care and support of older people with learning disabilities in health settings?
Quality of evidence	Recommendation 1.1.5 is based on the review of evidence for questions 9 about the care and support of older people with learning disabilities in health settings and due to there being some overlap with the NICE guideline on service user experience in adult mental health, the recommendation is adapted from this guideline. Overall, for question 9, 6 studies were located and they were moderate to good in terms of internal validity. Practitioner, service user and family views were all represented, providing useful insight into the experiences and preferences of older people with learning disabilities in relation to health assessments and interaction with practitioners although there were clear gaps in evidence about the perspective of health practitioners e.g. hospital practitioners or GPs. Recommendation 1.1.5 is also informed by research located for question 5 about access and referral to health, social care and housing services. The evidence located for review question 5 (n=7) was moderate to good in terms of internal validity and provided data on the views and experiences of older people with learning disabilities, their families and carers and also of practitioners. There was no effectiveness evidence and the views and experiences data focussed on barriers to access rather than means of improving access and referral. Recommendation 1.1.6 is based on evidence reviewed for question 5, the quality of which is described above. It is also based on evidence reviewed for questions 1 and 2 about the identification, assessment and review of care and support needs among older people with learning disabilities. For question 1, there were 7 studies, which on average were moderate in terms

	of their internal validity. Only 1 study of moderate quality specifically answered question 2 and a further 4 studies provided data to answer both questions 1 and 2 because they reported practitioner views as well as views of older people with learning disabilities and their carers or families. There were gaps in the evidence about assessment and review of needs, with most of the data covering future planning. The gaps in the data led to discussions based on committee expertise, with crucial input from the experts by experience, including carers. Recommendation 1.1.7 is based on evidence from review question 9 about care and support for older people with learning disabilities in health settings. Overall, for question 9, 6 studies were located and they were moderate to good in terms of internal validity. Practitioner, service user and family views were all represented, providing useful insight into the experiences and preferences of older people with learning disabilities in relation to health assessments and interaction with practitioners although there were clear gaps in evidence about the perspective of health practitioners e.g. hospital practitioners or GPs. Recommendation 1.1.8 is based on evidence from review questions 1 and 2, the quality of which is described above.
Economic considerations	The guideline committee agreed that whilst there were costs associated with the additional information and communication support, this was likely to be offset by reductions in 'wasted' appointments. The guideline committee reported that it was common that appointments were repeated and unnecessarily lengthy because of poor communication and misunderstandings. In addition, health conditions were identified at a late stage contributing to substantial suffering and more costly, intensive services for diseases identified at a late stage.
Evidence statements – numbered evidence statements from which the recommendations were developed	HS1: There is a small amount of evidence that health practitioners do not communicate well with older people with learning disabilities, resulting in poor health care experiences. One study (Webber et al. 2010 ++) reported a particular concern among carers was a lack of, or inappropriate communication from hospital staff, for example when talking to patients about treatment they could not understand. Practitioners also failed to take time to interact with older people with learning disabilities. This could lead to misunderstandings (p8). Another study (Fender et al. 2007 ++) reported that older people with learning disabilities agreed that doctors should be sensitive about the questions they ask people during examinations. They also recommended ways that doctors can diagnose problems when a person is unable to communicate (p3). (Recommendations 1.1.5 and 1.1.7) AR2: There is some evidence that older people with learning disabilities can lack understanding and awareness about the importance of health interventions and this can limit their access to services. The quality of this evidence is mainly moderate. Mac Giolla Phadraid et al. (2014 +) found that irregular dentist attenders made a choice not to access this service – sometimes out of fear – or because they were unaware of the importance of dental checks (p1). Dodd et al. (2009 +) found that one of the reasons older adults were not accessing specialist learning

	disability services was that individuals themselves did not want this support (p12). McIlfatrick et al (2011 ++) identified a lack of understanding about breast examinations and breast cancer among women with learning disabilities, which acted as a barrier to accessing breast screening services (p15). (Recommendation 1.1.5) AR5: There is a moderate amount of evidence that family carers have an important influence over whether older people with learning disabilities access support. The quality of the evidence is moderate to good. In the study by Dodd et al (2009 +) key workers said that one of the reasons older people with learning disabilities do not access specialist services is that families opt to support the person themselves and feel that formal services are therefore not necessary (p12). A US study by Coyle et al. (2016 +) reported that it can sometimes be problematic if families telephone the resource centre seeking financial or benefits advice for the person with learning disabilities unless they are established as the legal representative (p9). Practitioners in the McIlfatrick et al. study (2011 ++) said that carers can be helpful in supporting women with learning disabilities to access breast cancer screening. On the other hand they can act as a barrier to access if they do not believe screening to be something the person needs or if they think it will cause too much distress (p15). Finally, in the study by Swaine at al. (2013 ++) carers said the reason the older person with learning disabilities had accessed good quality health care was that they had themselves acted as the person's champion (p3). (Recommendation 1.1.6) IAR6: There is some evidence that planning for the future of older people with learning disabilities should involve the whole family, including the person themselves. A moderate quality study by Coyle et al (2014 +) highlighted the importance of future planning with regard to the sibling role. Siblings said they needed to plan for a situation in which their parents could no longer provide care. Where parents had made future plans, a moderate quality study (Dillenberger and McKerr 2011 +) reported that they involved transferring the family home and caring responsibilities to non-learning-disabled children. On the other hand parents interviewed in a good quality study (Hole et al. 2013 ++) said they did not want their other children to be "burdened" with caring for their sibling. The results of this study point to the importance of early planning that balances the needs and desires of ageing adults with learning disabilities and family members. Finally, Bowey and McGlaughlin (2005 +) found that in situations of 'mutual caring', adults with learning disabilities were reluctant to move away to shared accommodation out of concern for how their parents will cope. This highlights that the line between carer and cared for is often blurred and everyone's wishes and needs must be considered during future planning. (Recommendation 1.1.8)
Other considerations	Recommendation 1.1.5 is informed by HS1 about the importance of ensuring enough time within appointments to make older people with learning disabilities feel comfortable, can ask questions and be given all the information needed. The recommendation is also based on evidence that older people with learning disabilities often lack understanding about health and

	health services. Reflecting on the combination of this evidence, the guideline committee agreed about the importance of an overarching recommendation to address people's information and communication needs in the context of care and support. In light of the legal requirements of the NHS Accessible Information Standard, this is a 'must' recommendation Recommendation 1.1.6 is based on evidence that families can sometimes act as gatekeepers if they do not believe the person should attend health screening. Committee members therefore agreed to a recommendation which ensured that older people with learning disabilities receive information about care and support in a way they understand so that they might make their own decisions and understand the different options. Given that evidence in IAR5 also showed that future housing arrangements are a key worry to older people with learning disabilities, the committee wished to ensure that accessible information about housing options is also provided. Recommendation 1.1.7 is based on evidence that health practitioners do not always communicate in an appropriate, accessible way, particularly during appointments and this results in poor health experiences. The committee agreed that in this context, the changing communication needs of adults with learning disabilities should be reviewed as they grow older. The guideline committee agreed that it was just as important for social care as well as health practitioners to assume this responsibility and it should apply as an overarching principle. Recommendation 1.1.8 is based on evidence in IAR6 about the importance of involving older people with learning disabilities in future planning. The guideline committee agreed this is relevant to decision making about care and support more broadly and wished to highlight that assessments of whether they people have capacity to make decisions about care and support must conducted within the context of the Mental Capacity Act 2005.

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Topic/section heading	**Involving people and their family members and carers**
Recommendations	1.1.9 Health and social care practitioners should listen to, actively involve and value key members of the person's support network in the planning and delivery of their current and future care and support, if the person agrees to this. Regularly check people's willingness and ability to be involved in this way. 1.1.10 Ask the person who they want to involve if they do not have close family members. Ensure they are aware of their right to an advocate and how to access this support. 1.1.11 Find out and prioritise the needs and preferences of the person. Ensure these are not overshadowed by the decisions or preferences of others, including when the person lacks capacity. 1.1.12 Be aware that older people with learning disabilities may need support to communicate their needs or retain information. With the person's consent, share information with their family members and carers, for example about:

	• any changes that might be needed to their care and support • symptoms, management and prognosis of the person's health conditions.
Research recommendations	The Guideline Committee agreed the following research recommendations to address gaps in evidence about the identification of health conditions, care and support at home, tele-monitoring, self-management and dementia training for families: Research recommendation 2 What is the effectiveness and cost effectiveness of different ways of identifying age-related and other physical and mental health conditions, in older people with learning disabilities? What can mainstream and specialist health services do to facilitate: - early identification of health conditions in older people with learning disabilities? - equal access to health services in older people with learning disabilities? Research recommendation 1 What is the effectiveness and cost effectiveness of care and support models (for example, assistive technology) for older people with learning disabilities to enable them to live at home with or without their family? Research recommendation 7 a) What is the effectiveness and cost-effectiveness of tele-monitoring in: - promoting understanding and improving management of chronic physical and mental health conditions for older people with learning disabilities? - supporting their ageing family carers to continue providing care? b) What are the mechanisms that make tele-monitoring accessible and acceptable to older people with learning disabilities? Research recommendation 3 What is the effectiveness and cost effectiveness of education programmes to improve information and advice and to support self-management of chronic health conditions (for example obesity, diabetes and cardiovascular disease) for older people with learning disabilities and their family members and carers? Research recommendation 4 What is the effectiveness, cost effectiveness and acceptability of training programmes (for example in the use of life story work) for families of older people with learning disabilities who have dementia or are at risk of developing it?
Review questions	1. What are the views and experiences of older people with learning disabilities and their carers about how care and support needs are identified, assessed and reviewed? 2. What are the views and experiences of health, social care and other practitioners about how the health and social care needs of

	older people with learning disabilities and their carers are identified, assessed and reviewed? 3a) What is the acceptability, effectiveness and cost effectiveness of providing information, advice and training to older people with learning disabilities? 3b) What are the views and experiences of older people with learning disabilities and their carers about information, advice and training to older people with learning disabilities? 3c) What are the views and experiences of health, social care and other practitioners about information, advice and training to older people with learning disabilities? 4a) What is the acceptability, effectiveness and cost effectiveness of providing information, advice, training and support for families, carers and advocates of older people with learning disabilities? 4b) What are the views and experiences of older people with learning disabilities and their carers about information, advice, training and support provided to families, carers and advocates? 4c) What are the views and experiences of health, social care and other practitioners about information, advice, training and support for families, carers and advocates? 5a) What is the acceptability, effectiveness and cost effectiveness of interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 5b) What are the views and experiences of older people with learning disabilities and their carers about interventions or approaches to improve access and referral to health, social care and housing support services? 5c) What are the views and experiences of health, social care and other practitioners about interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 7a) What is the acceptability, effectiveness and cost effectiveness of care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities? 7b) What are the views and experiences of people using services and their carers in relation to care at home, in supported housing or accommodation with care and support for older people with learning disabilities? 7c) What are the views and experiences of health, social care and other practitioners about care and support at home, in supported housing or accommodation with care and support for older people with learning disabilities?
Quality of evidence	Recommendation 1.1.9 is based on evidence from review question 5 about access and referral to health, social care and housing services. The evidence located for review question 5 (n=7) was moderate to good in terms of internal validity and provided data on the views and experiences of older people with learning disabilities, their families and carers and also of practitioners. There was no effectiveness evidence and the views

	and experiences data focussed on barriers to access rather than means of improving access and referral. Recommendation 1.1.9 was also supported by evidence from review question 4 about information, training and advice for families, carers and advocates of older people with learning disabilities. Four papers were reviewed for question 4 and they provided data about the views and experiences of older people with learning disabilities and their families although no data on practitioner views. Overall, the internal validity of the studies was judged to be moderate. The studies focused on gaps in information, training and support needs for carers of older people. There was a lack of evidence trialling approaches or interventions, and gaps in evidence about training programmes for older people with learning disabilities, in terms of how best to provide them and how effective they are. Recommendation 1.1.10 was based on evidence reviewed for questions 1 and 2 about the identification, assessment and review of care and support needs among older people with learning disabilities. For question 1, there were 7 studies, which on average were moderate in terms of their internal validity. Only 1 study of moderate quality specifically answered question 2 and a further 4 studies provided data to answer both questions 1 and 2 because they reported practitioner views as well as views of older people with learning disabilities and their carers or families. There were gaps in the evidence about assessment and review of needs, with most of the data covering future planning. The gaps in the data led to discussions based on committee expertise, with crucial input from the experts by experience, including carers. Recommendation 1.1.11 is based on evidence informed by research located for question 5 about access and referral to health, social care and housing services. The evidence located for review question 5 (n=7) was moderate to good in terms of internal validity and provided data on the views and experiences of older people with learning disabilities, their families and carers and also of practitioners. There was no effectiveness evidence and the views and experiences data focussed on barriers to access rather than means of improving access and referral. Recommendation 1.1.12 is based on evidence from review question 9 about care and support for older people with learning disabilities in health settings. Overall, for question 9, 6 studies were located and they were moderate to good in terms of internal validity. Practitioner, service user and family views were all represented, providing useful insight into the experiences and preferences of older people with learning disabilities in relation to health assessments and interaction with practitioners although there were clear gaps in evidence about the perspective of health practitioners e.g. hospital practitioners or GPs. Recommendation 1.1.12 is also supported by evidence located for review question 3 about information, training and advice for older people with learning disabilities. A total of 6 papers were included for this question and overall, their internal validity was good to moderate. Only one effectiveness study was found, although the results were of limited use due to methods issues. The views and experiences or older people with learning disabilities and their families were well represented in the evidence but only one study

	provided the practitioner perspective. The views studies provided important information about what works and what does not in providing information. There was a particular lack of evidence trialling approaches or interventions, and a gap in evidence about training for older people with learning disabilities, whether it is needed and how best to provide it.
Economic considerations	No economic evidence was identified. The guideline committee provided a number of examples of the negative consequences if carers and support networks were not included in the person's care and examples of the potential benefits if they were included. The carer often carried out tasks that would otherwise need to be carried out by a professional. This referred to care provided in the person's home as well as in health and social care setting. For example, carer could ensure that person would be able to get food and stay hydrated. This would otherwise require substantial amounts of professionals' time. Including the carer and support network was thus seen as an important part of cost-effective care from a government budget perspective.
Evidence statements – numbered evidence statements from which the recommendations were developed	AR5: There is a moderate amount of evidence that family carers have an important influence over whether older people with learning disabilities access support. The quality of the evidence is moderate to good. In the study by Dodd et al (2009 +) key workers said that one of the reasons older people with learning disabilities do not access specialist services is that families opt to support the person themselves and feel that formal services are therefore not necessary (p12). A US study by Coyle et al. (2016 +) reported that it can sometimes be problematic if families telephone the resource centre seeking financial or benefits advice for the person with learning disabilities unless they are established as the legal representative (p9). Practitioners in the McIlfatrick et al. study (2011 ++) said that carers can be helpful in supporting women with learning disabilities to access breast cancer screening. On the other hand they can act as a barrier to access if they do not believe screening to be something the person needs or if they think it will cause too much distress (p15). Finally, in the study by Swaine at al. (2013 ++) carers said the reason the older person with learning disabilities had accessed good quality health care was that they had themselves acted as the person’s champion (p3). (Recommendations 1.1.9 and 1.1.11) FCA1: There is a small amount of evidence that families of older people with learning disabilities are not given the support and information needed to take an active role in planning. The quality of the evidence is moderate. A UK study by Atkins and Loverseed (2012 +) found that some carers felt excluded from care planning and this was attributed to not being sufficiently well informed about the older person’s health condition (p1). Another UK study by Tozer and Atkin (2015 +) found that siblings of older people with learning disabilities wanted to take on more responsibilities in future and wanted support from professionals to do this. They felt that in general, professionals were not proactive in involving them in future planning (p8). (Recommendation 1.1.9) IAR6: There is some evidence that planning for the future of older people with learning disabilities should involve the whole family, including the person themselves. A moderate quality study by

	Coyle et al (2014 +) highlighted the importance of future planning with regard to the sibling role. Siblings said they needed to plan for a situation in which their parents could no longer provide care. Where parents had made future plans, a moderate quality study (Dillenberger and McKerr 2011 +) reported that they involved transferring the family home and caring responsibilities to non-learning-disabled children. On the other hand parents interviewed in a good quality study (Hole et al. 2013 ++) said they did not want their other children to be "burdened" with caring for their sibling. The results of this study point to the importance of early planning that balances the needs and desires of ageing adults with learning disabilities and family members. Finally, Bowey and McGlaughlin (2005 +) found that in situations of 'mutual caring', adults with learning disabilities were reluctant to move away to shared accommodation out of concern for how their parents will cope. This highlights that the line between carer and cared for is often blurred and everyone's wishes and needs must be considered during future planning. (Recommendation 1.1.10) HS1: There is a small amount of evidence that health practitioners do not communicate well with older people with learning disabilities, resulting in poor health care experiences. One study (Webber et al. 2010 ++) reported a particular concern among carers was a lack of, or inappropriate communication from hospital staff, for example when talking to patients about treatment they could not understand. Practitioners also failed to take time to interact with older people with learning disabilities. This could lead to misunderstandings (p8). Another study (Fender et al. 2007 ++) reported that older people with learning disabilities agreed that doctors should be sensitive about the questions they ask people during examinations. They also recommended ways that doctors can diagnose problems when a person is unable to communicate (p3). (Recommendation 1.1.12) IAT1: There is a moderate amount of evidence that advice about health experiences is not always presented clearly enough for older people with learning disabilities. This leads to confusion and a lack of understanding. The quality of this evidence is moderate to good. A study from the Netherlands (Cardol et al. 2012 ++) found that not one of the participants had received written information about their health condition (diabetes) in a way they could understand (p3). A UK study by Willis (2008 +) also found that 12 out 18 respondents had received no information about the menopause and for 3 women, the television had been their source of information. Any information that had been provided was produced in an inappropriate format (p4). Another UK study by Young et al. (2012) emphasized that information for older people with learning disabilities needs to be presented in a meaningful way so they can manage their heart condition (p6). Finally, Willis et al. 2010 (+) found that care workers wanted specific training to help them communicate with older women with learning disabilities and provide them with advice and support through the menopause (p8). (Recommendation 1.1.12)
Other considerations	Recommendation 1.1.9 is based on AR5 about the important role that families and carers play in supporting older people with learning disabilities to access care and support. It is also

	supported by FCA1, which reports that families do not feel valued by professionals. The committee therefore agreed a recommendation to ensure that their contribution is recognised and their role is supported. They thought it more relevant to refer to people's 'support networks' rather than limiting to families and through discussion they also agreed about the importance of reviewing the support that people feel they can provide; after all this is unlikely to remain constant and indeed some people may not feel able or inclined to help. Recommendation 1.1.10 is based on IAR6 about the importance of involving the whole family in planning for the future or indeed in any discussions about care and support. In discussing this evidence the guideline committee acknowledged that some older people with learning disabilities do not have close family members and in these situations it is important to ask the person who they would instead like to involve in those planning discussions. Recommendation 1.1.11 is based on AR5 about the important role that families can have in supporting older people with learning disabilities to access care and support. Some of the evidence (including McIlfratick et al. 2011, ++) demonstrated that it is not always a positive influence and this resonated with the members' experience. They therefore agreed to a recommendation that would ensure that the needs and preferences of the person are prioritised and not overshadowed but other people's opinions. Although the evidence pertained to health settings, the committee agree that the recommendation should be broadened to be the responsibility of providers of all care and support. Recommendation 1.1.12 is based on evidence in HS1 that practitioners do not communicate well with older people with learning disabilities, resulting in negative health experiences. It is supported by evidence from IAT1 that health advice is not always presented clearly enough for older people with learning disabilities to understand. This recommendation therefore highlights the importance of ensuring that older people with learning disabilities have the support the need to express their health needs or to retain information about their treatment or condition. In light of the other recommendations about the role of families, the committee also agreed to highlight that with the person's consent, their families should also be provided with this information.

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Topic/section heading	**Organising and delivering services to help people live a good life - planning and commissioning local services**
Recommendations	1.2.1 Health and social care commissioners should have an understanding of the needs of older people with learning disabilities in their area and know what mainstream and specialist services are available locally to support people as they grow older.

	1.2.2 Commissioners should identify the number of households that include an adult with a learning disability, and use this information to identify gaps in provision, organise services and plan future provision. This could be done by encouraging GPs to develop and maintain registers of people with learning disabilities and getting information from other support services, including education and the Department for Work and Pensions. 1.2.3 Commissioners and service providers should provide family members, carers and advocates of older people with learning disabilities with age-appropriate community support services and resources to such as: • day opportunities • short respite breaks (both at home and away from home) • family placements • support groups for family carers, including siblings, and for older people with learning disabilities who have caring responsibilities • a single point of contact for practical information, emotional support and signposting.
Research recommendations	The Guideline Committee agreed the following research recommendations to address gaps in evidence about identifying health conditions, models of care at home, tele-monitoring and dementia training for families: Research recommendation 1 What is the effectiveness and cost effectiveness of care and support models (for example, assistive technology) for older people with learning disabilities to enable them to live at home with or without their family? Research recommendation 2 a) What is the effectiveness and cost effectiveness of different ways of identifying age-related and other physical and mental health conditions, in older people with learning disabilities? b) What can mainstream and specialist health services do to facilitate: - early identification of health conditions in older people with learning disabilities? - equal access to health services in older people with learning disabilities? Research recommendation 7 a) What is the effectiveness and cost effectiveness of telemonitoring for older people with learning disabilities in: - promoting understanding and improving management of chronic physical and mental health conditions? - supporting their ageing family carers to continue providing care? b) What are the mechanisms that make telemonitoring accessible and acceptable to older people with learning disabilities? Research recommendation 4 What is the effectiveness, cost effectiveness and acceptability of training programmes (for example in the use of life story work) for

	families of older people with learning disabilities who have dementia or are at risk of developing it?
Review questions	4a) What is the acceptability, effectiveness and cost effectiveness of providing information, advice, training and support for families, carers and advocates of older people with learning disabilities? 4b) What are the views and experiences of older people with learning disabilities and their carers about information, advice, training and support provided to families, carers and advocates? 4c) What are the views and experiences of health, social care and other practitioners about information, advice, training and support for families, carers and advocates? 5a) What is the acceptability, effectiveness and cost effectiveness of interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 5b) What are the views and experiences of older people with learning disabilities and their carers about interventions or approaches to improve access and referral to health, social care and housing support services? 5c) What are the views and experiences of health, social care and other practitioners about interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 7a) What is the acceptability, effectiveness and cost effectiveness of care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities? 7b) What are the views and experiences of people using services and their carers in relation to care at home, in supported housing or accommodation with care and support for older people with learning disabilities? 7c) What are the views and experiences of health, social care and other practitioners about care and support at home, in supported housing or accommodation with care and support for older people with learning disabilities?
Quality of evidence	Recommendation 1.2.1 is based on evidence from question 5 about access and referral to health, social care and housing services. The evidence located for review question 5 (n=7) was moderate to good in terms of internal validity and provided data on the views and experiences of older people with learning disabilities, their families and carers and also of practitioners. There was no effectiveness evidence and the views and experiences data focussed on barriers to access rather than means of improving access and referral. Recommendation 1.2.2 is based on evidence from review question 7 about care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities. A total of 8 papers were reviewed for this question although there was very little effectiveness evidence, with data found in just 1 study. Data on views and experiences were mainly from the practitioner perspective (n=5), on supporting adults with learning disabilities in group homes as they grow older

	and supporting adults with learning disabilities in residential care for older people. There were gaps in evidence about the effectiveness and experiences of care and support in the family home, which had implications for developing recommendations and drawing on other evidence, in particular expert testimony. Recommendation 1.2.3 is based on evidence from review 4 about information, training and advice for families, carers and advocates of older people with learning disabilities. Four papers were reviewed for question 4 and they provided data about the views and experiences of older people with learning disabilities and their families although no data on practitioner views. Overall, the internal validity of the studies was judged to be moderate. The studies focused on gaps in information, training and support needs for carers of older people. There was a lack of evidence trialling approaches or interventions, and gaps in evidence about training programmes for older people with learning disabilities, in terms of how best to provide them and how effective they are.
Economic considerations	No economic evidence was identified. The guideline committee agreed that providing respite opportunities was very important in ensuring that carers were able to continue caring. There was a great risk that if carer did not get the support they needed that this would cause a family breakdown, which could lead to the person and/or their carer having to move into residential care. Thus, the guideline committee thought that there was a strong economic rationale for governments to pay for the additional support as they might otherwise have to pay for much more expensive residential care for at least one person.
Evidence statements – numbered evidence statements from which the recommendations were developed	AR3: There is a moderate amount of evidence that older people with learning disabilities have limited access to support because of a lack of services designed specifically to address their needs and preferences. The quality of the evidence is mostly moderate. Wark et al. (2015 ++) found that in rural Australia, older people with learning disabilities had to travel very long distances from home in order to access specialist health services. In addition, where learning disability services were available locally, access was limited by having few, if any, options (p5). Benbow et al. (2011 +) reported that learning disability practitioners said psychiatry services for older people in the UK specifically exclude people with learning disabilities (p8). The US study by Coyle (2016 +) reported clear difficulties from a practitioner perspective around being able to provide resources and support to older people with learning disabilities. As a result staff admitted to not addressing the needs of the specific population in the provision of services although it was something they recognized they ought to in future (p9). Finally, a study conducted in Ireland (Dodd et al. 2009 +) found that one of the reasons older adults with learning disabilities did not access specialist learning disability services was that families judged that they were not appropriate to meet the person’s needs (p12). (Recommendation1.2.1) H7: No evidence was found from studies published since 2005 about the effectiveness or the experience of care and support for older people with learning disabilities living in the family home. Six of the included studies were based in residential settings – often group homes – for adults with learning disabilities: Nambisan

	(2014 +), Forbat (2008 +), Iacano (2014 ++), Kåhlin (2015 ++), Maes and Van Puyenbroeck (2008 ++) and Webber (2010 +). One of the included studies was based in residential settings for older people (Bigby 2008 +). (Recommendation 1.2.2) FCA3: There is a small amount of evidence that support needs for families and carers of older people with learning disabilities and dementia are not being met. The quality of the evidence is moderate. The study by Atkins and Loverseed (2012 +) reported that some family carers were reluctant to ask for formal support because of past negative experiences with professionals and services (p1). The UK study by McLaughlin and Jones (2011 +) found that carers' support needs increased after the older person with a learning disability had been diagnosed with dementia, for example because of the increase in medical appointments. Families and carers needed to access respite services but did not know how (p5). The American study by Janicki et al. (2010 +) also found that carers had unmet needs from respite services (p4). (Recommendation 1.2.3)
Other considerations	Recommendation 1.2.1 is based on evidence in AR3 which reports that there are a lack of services designed specifically to support the needs of older people with learning disabilities. The committee agreed that this is the case in practice and the commissioners should have responsibility for ensuring appropriate services are made available by understanding local population needs. Recommendation 1.2.2 is based on H7 which highlights a lack of evidence about the effectiveness of care and support for older people with learning disabilities living in their own or the family home. Combined with their own experience in this area and with the evidence from AR3 (described above) the committee agreed that this reflected a lack of specific provision of support for people living at home. They therefore reached a consensus that commissioners should identify the number of households that include an adult with a learning disability and use this information to organise support and plan for future provision as the population ages. Recommendation 1.2.3 is based on FCA3 which reports evidence that there is a lack of support available to families and carers of older people with learning disabilities. The committee agreed that this reflects the current situation and they debated what kinds of support would benefit families. They agreed with the findings in Janicki et al. (2010 +) that respite services are crucial and through consensus they cited other examples such as support groups and signposting of information. In the committee's view, it is the responsibility of commissioners and providers to ensure this support is in place.

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Topic/section heading	**Planning and commissioning local services (continued)**

Recommendations	1.2.4 Commissioners and service providers should provide housing options that meet the changing needs of people with learning disabilities as they grow older. This includes: • making reasonable adjustments to accommodate their changing physical and emotional needs • providing equipment or housing adaptations • ensuring accessible transport links are available to help people access local facilities • arranging housing for older people with learning disabilities who are in unstable housing situations, for example those who are homeless or in temporary accommodation (including people seeking asylum). 1.2.5 Commissioners should make available locally a wide range of housing, family and community support options to meet the needs of older people with learning disabilities, as they grow older, including people in later old age and their family members and carers. These might include: • access to advocacy services • respite care • in-home support (such as physical adaptations) • supported living • residential and nursing care which reflect gender, sexual orientation and cultural preferences.
Research recommendations	The Guideline Committee agreed the following research recommendation to address gaps in evidence about identifying health conditions, models of support at home and tele-monitoring: Research recommendation 1 What is the effectiveness and cost effectiveness of care and support models (for example, assistive technology) for older people with learning disabilities to enable them to live at home with or without their family? Research recommendation 2 a) What is the effectiveness and cost effectiveness of different ways of identifying age-related and other physical and mental health conditions, in older people with learning disabilities? b) What can mainstream and specialist health services do to facilitate: - early identification of health conditions in older people with learning disabilities? - equal access to health services in older people with learning disabilities? Research recommendation 7 a) What is the effectiveness and cost effectiveness of telemonitoring for older people with learning disabilities in: - promoting understanding and improving management of chronic physical and mental health conditions? - supporting their ageing family carers to continue providing care?

Review questions	1. What are the views and experiences of older people with learning disabilities and their carers about how care and support needs are identified, assessed and reviewed? 2. What are the views and experiences of health, social care and other practitioners about how the health and social care needs of older people with learning disabilities and their carers are identified, assessed and reviewed? 7a) What is the acceptability, effectiveness and cost effectiveness of care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities? 7b) What are the views and experiences of people using services and their carers in relation to care at home, in supported housing or accommodation with care and support for older people with learning disabilities? 7c) What are the views and experiences of health, social care and other practitioners about care and support at home, in supported housing or accommodation with care and support for older people with learning disabilities? 9a) What are the views and experiences of older people with learning disabilities and their carers about care and support in health settings? 9b) What are the views and experiences of health, social care and other practitioners about the care and support of older people with learning disabilities in health settings?
Quality of evidence	Recommendation 1.2.4 is based on evidence from questions 1 and 2 about the identification, assessment and review of care and support needs among older people with learning disabilities. Due to the overlap with the NICE guideline on older people with social care needs and multiple long term conditions, the recommendation was adapted from that guideline. For question 1, there were 7 studies, which on average were moderate in terms of their internal validity. Only 1 study of moderate quality specifically answered question 2 and a further 4 studies provided data to answer both questions 1 and 2 because they reported practitioner views as well as views of older people with learning disabilities and their carers or families. There were gaps in the evidence about assessment and review of needs, with most of the data covering future planning. The gaps in the data led to discussions based on committee expertise, with crucial input from the experts by experience, including carers. It is also supported by evidence from review question 7 about care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities. A total of 8 papers were reviewed for this question although there was very little effectiveness evidence, with data found in just 1 study. Data on views and experiences were mainly from the practitioner perspective (n=5), on supporting adults with learning disabilities in group homes as they grow older and supporting adults with learning disabilities in residential care for older people. There were gaps in evidence about the effectiveness and experiences of care and support in the family

	home, which had implications for developing recommendations and drawing on other evidence, in particular expert testimony. Recommendation 1.2.5 is based on evidence from review questions 1 and 2, the quality of which is described above.
Economic considerations	No economic evidence was identified. The guideline committee thought that providing support so that the person could stay at their home was a key priority. The guideline committee agreed that the person was likely to live with better mental health if they could stay in their own home. In particular taking away the current support network could have a detrimental impact on the person's mental and general health causing further deterioration, social isolation and greater health and social care needs. Whilst the GC recognised that providing the appropriate care package (including in form of adaptations) might be linked to additional costs, they thought that this was extremely important. They also thought that on average this was less costly than paying for the alternative, which usually involved large government expenditures for paying nursing home or residential care for the person with learning disability as well as potentially another family member (if the person was caring for someone). Another important consideration was also that placements were often in a different catchment requiring carers and family members to travel long distances, which could cause substantial problems including financial ones.
Evidence statements – numbered evidence statements from which the recommendations were developed	IAR1: There is a small of good quality evidence that practitioners supporting adults with learning disabilities feel they cannot continue to provide care throughout the person's 'old' age. One good quality study (Bigby et al. 2011 ++) found that when a person's medical or personal care needs reached a certain level they would have to move to an aged care environment. The point at which their needs reached this level was subjective and variable and it was hard for families to anticipate. (Recommendation 1.2.4) H5: There is some evidence that adults with learning disabilities can have poor experiences and quality of life when they live in residential care settings for older people. The quality of the evidence is mainly moderate. Bigby et al. (2008 +) reported that adults with learning disabilities often had no meaningful relationships with other residents, more often befriending staff. This is particularly the case where there are only a small number of adults with learning disabilities living in the care home (p7). Iacono (2014 ++) found that staff in group homes wanted their residents to stay as long as possible because they did not believe they would receive specialist care for learning disabilities if they moved to a care home (p10). Similarly, some respondents in the Webber study (2010 +) felt group home residents would be better supported there than in a residential home and said that every possible adjustment should be made so they could stay. On the other hand, some respondents felt that it was in everyone's best interests if people with learning disabilities move to residential care as they grow older and less independent (p17). (Recommendation 1.2.4) IAR6: There is some evidence that planning for the future of older people with learning disabilities should involve the whole family,

	including the person themselves. A moderate quality study by Coyle et al (2014 +) highlighted the importance of future planning with regard to the sibling role. Siblings said they needed to plan for a situation in which their parents could no longer provide care. Where parents had made future plans, a moderate quality study (Dillenberger and McKerr 2011 +) reported that they involved transferring the family home and caring responsibilities to non-learning-disabled children. On the other hand parents interviewed in a good quality study (Hole et al. 2013 ++) said they did not want their other children to be "burdened" with caring for their sibling. The results of this study point to the importance of early planning that balances the needs and desires of ageing adults with learning disabilities and family members. Finally, Bowey and McGlaughlin (2005 +) found that in situations of 'mutual caring', adults with learning disabilities were reluctant to move away to shared accommodation out of concern for how their parents will cope. This highlights that the line between carer and cared for is often blurred and everyone's wishes and needs must be considered during future planning. (Recommendation 1.2.5)
Other considerations	Recommendation 1.2.4 is based on IAR1 and H5. Evidence reported in IAR1 demonstrates that as adults with learning disabilities age, providers often feel they can no longer provide appropriate support. On this basis the committee agreed that commissioners and providers should have responsibility to ensure that accommodation options are in place that meet the changing needs of older people with learning disabilities. H5 reports evidence that when older people with learning disabilities live in care homes for older people they often have poor experiences, including feeling isolated. For this reason the committee agreed to include the first bullet to ensure that reasonable adjustments are made to address people's changing needs in their own accommodation, therefore reducing the likelihood of having to move to a care home for their needs to be met. The committee discussed the range of other actions that could be taken to ensure that people's needs are met, even as they grow older. These were agreed through consensus and are provided as a list of suggestions for commissioners and providers in 1.2.4 Recommendation 1.2.5 is based on IAR6 about the importance of future planning that includes the whole family, including the older person themselves. The evidence also highlighted that the line between carer and cared for is often blurred with adults with learning disabilities distressed at the prospect of leaving the family home when their parents still rely on them. The committee therefore agreed this recommendation that commissioners should ensure a wide range of housing and community support options are available to address the needs of the person and their families whether they live in supported accommodation or wish to remain living in the family home. In discussing this recommendation the group felt they wanted to refer to the potential role of tele-monitoring and since they did not have the evidence to support this they developed a research recommendation to address this perceived gap.

Topic/section heading	**Planning and commissioning local services (continued)**
Recommendations	1.2.6 Consider the use of telehealth and telecare for older people with learning disabilities, their family members and carers, and relevant partners such as GPs and adult social care services. 1.2.7 Clinical commissioning groups should identify where there are gaps in community optometry and dental services for older people with learning disabilities and address those gaps. 1.2.8 Mental health commissioners should develop protocols to ensure that older people with learning disabilities, including people in later old age, have access to mainstream mental health services for older people, including dementia support.
Research recommendations	The Guideline Committee agreed the following research recommendations to address gaps in evidence about the identification of health conditions, care and support at home and tele-monitoring to manage health conditions: Research recommendation 1 What is the effectiveness and cost effectiveness of care and support models (for example, assistive technology) for older people with learning disabilities to enable them to live at home with or without their family? Research recommendation 2 a) What is the effectiveness and cost effectiveness of different ways of identifying age-related and other physical and mental health conditions, in older people with learning disabilities? b) What can mainstream and specialist health services do to facilitate: - early identification of health conditions in older people with learning disabilities? - equal access to health services in older people with learning disabilities? Research recommendation 7 a) What is the effectiveness and cost effectiveness of telemonitoring for older people with learning disabilities in: - promoting understanding and improving management of chronic physical and mental health conditions? - supporting their ageing family carers to continue providing care? b) What are the mechanisms that make telemonitoring accessible and acceptable to older people with learning disabilities?
Review questions	5a) What is the acceptability, effectiveness and cost effectiveness of interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 5b) What are the views and experiences of older people with learning disabilities and their carers about interventions or approaches to improve access and referral to health, social care and housing support services? 5c) What are the views and experiences of health, social care and other

	practitioners about interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 7a) What is the acceptability, effectiveness and cost effectiveness of care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities? 7b) What are the views and experiences of people using services and their carers in relation to care at home, in supported housing or accommodation with care and support for older people with learning disabilities? 7c) What are the views and experiences of health, social care and other practitioners about care and support at home, in supported housing or accommodation with care and support for older people with learning disabilities?
Quality of evidence	Recommendation 1.2.6 is based on evidence reviewed for review question 7 about care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities. A total of 8 papers were reviewed for this question although there was very little effectiveness evidence, with data found in just 1 study. Data on views and experiences were mainly from the practitioner perspective (n=5), on supporting adults with learning disabilities in group homes as they grow older and supporting adults with learning disabilities in residential care for older people. There were gaps in evidence about the effectiveness and experiences of care and support in the family home, which had implications for developing recommendations and drawing on other evidence, in particular expert testimony. Recommendations 1.2.7 and 1.2.8 are both based on evidence reviewed for review question 5 about access and referral to health, social care and housing services. The evidence located for review question 5 (n=7) was moderate to good in terms of internal validity and provided data on the views and experiences of older people with learning disabilities, their families and carers and also of practitioners. There was no effectiveness evidence and the views and experiences data focussed on barriers to access rather than means of improving access and referral.
Economic considerations	No economic evidence was identified. There is currently no economic evidence to support the cost-effectiveness of telehealth and telecare for this population, or to suggest the opposite. There might be cost savings linked to telehealth and telecare as they might help people to live independently in their home, and prevent the use of more expensive health and other social care (such as hospital admissions linked to falls). However, this would need to be confirmed in economic evaluations of technologies and of care packages that support the use of such technologies.
Evidence statements – numbered evidence statements from which the	H4: There is a small amount of evidence that telemonitoring improves outcomes and experiences for older people with learning disabilities. The quality of that evidence is moderate. The study by Nambisan et al. (2014 +) found that telemonitoring helped residents understand their conditions better and made them feel more independent. Staff said it gave them greater

recommendations were developed	insight into the condition of the residents (p1). (Recommendation 1.2.6) AR1: There is a small amount of evidence that older people with learning disabilities who live independently have poor access to dental care. The quality of the evidence is moderate. Mac Giolla Phadraig et al. (2014 +) found that the proportion of regular dentist attenders was lowest among people living independently and this is perhaps owing to the fact that dentists generally visit selected residential services on an annual basis (p1). (Recommendation 1.2.7) AR3: There is a small amount of evidence that older people with learning disabilities who live independently have poor access to dental care. The quality of the evidence is moderate. Mac Giolla Phadraig et al. (2014 +) found that the proportion of regular dentist attenders was lowest among people living independently and this is perhaps owing to the fact that dentists generally visit selected residential services on an annual basis (p1). (Recommendation 1.2.8)
Other considerations	Recommendation 1.2.6 is based on a small amount of evidence reported in H4 that tele-monitoring improves outcomes for older people with learning disabilities. The guideline committee agreed with the research findings so they recommended the use of telehealth and telecare for supporting older people with learning disabilities. The group reflected the small amount of supporting evidence by making this a weak, ‘consider’ recommendation. Given the lack of evidence about the use of these technologies with this specific population the committee also agreed a research recommendation for future work in this area. Recommendation 1.2.7 is based on AR1 which reports evidence that older people with learning disabilities living in the community have poor access to dental care. The committee responded by agreeing this recommendation that clinical commissioning groups should identify where there are such gaps in dental services, which are suited to older people with learning disabilities and they should address those gaps. Recommendation 1.2.8 is based on AR3 which reports a lack of services to address the needs of older people with learning disabilities. Although the evidence highlighted a lack of specialist services, the committee actually felt strongly that mainstream services ought to be accessible to older people with learning disabilities. Because of the connection between learning disabilities and dementia the committee agreed it was particularly important to emphasise the need for mainstream mental health services to be fully accessible. They agreed it was the responsibility of mental health commissioners to encourage inclusion through the development of service protocols

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Topic/section heading	**Planning and commissioning local services (continued)**
Recommendations	1.2.9 Commissioners and service providers should ensure that older people with learning disabilities have equal access to a

	range of community services that reflect the cultural diversity of the local area and people's hopes, preferences, choices and abilities as they grow older. 1.2.10 Commissioners and providers should establish links between specialist learning disability services and mainstream older people's services. This could be done by bringing them together to help identify gaps and inform service development, sharing information and learning, and linking into voluntary sector umbrella groups. 1.2.11 Commissioners and providers should provide opportunities for older people with learning disabilities to meet up and socialise, for instance through social clubs and support groups. 1.2.12 Commissioners and providers should ensure there is a wide range of community-based physical activity programmes available and encourage people to take part to promote their health and wellbeing. Examples include dancing, swimming, bowls, using the gym, organised walks and chair-based exercise classes. 1.2.13 Commissioners and providers should arrange accessible opportunities for older people with learning disabilities to engage in education, working and volunteering. 1.2.14 Local authorities should consider introducing schemes to make transport easier for older people with learning disabilities. For example: • providing free travel such as London's 'Freedom pass' • using minibuses as community transport • starting 'buddy' schemes to enable independent travel • developing transport especially for people living in rural locations • schemes such as 'JAM' cards (Just A Minute) – which can be used to alert transport staff that people have a learning disability • schemes to help people with a personal budget to travel to activities and self-advocacy groups.
Research recommendations	The Guideline Committee agreed the following research recommendations to address gaps in evidence about personalised technology for promoting social relations and self management for health conditions: Research recommendation 3 What is the effectiveness and cost effectiveness of education programmes to improve information and advice and to support self-management of chronic health conditions (for example obesity, diabetes and cardiovascular disease) for older people with learning disabilities and their family members and carers? Research recommendation 6 What is the effectiveness and cost effectiveness of personal technology and social media to help older people with learning disabilities to maintain relationships with friends and family, build

	social contacts and access volunteering, social and leisure activities?
Review questions	3a) What is the acceptability, effectiveness and cost effectiveness of providing information, advice and training to older people with learning disabilities? 3b) What are the views and experiences of older people with learning disabilities and their carers about information, advice and training to older people with learning disabilities? 3c) What are the views and experiences of health, social care and other practitioners about information, advice and training to older people with learning disabilities? 6a) What is the acceptability, effectiveness and cost effectiveness of care planning and support for older people with learning disabilities to access volunteering, employment and adult learning, social and leisure activities, transport and technology and maintain relationships with family, friends and within their local community? 6b) What are the views and experiences of older people and their carers in relation to support for developing and maintaining relationships with family, friends and the local community? 6c) What are the views and experiences of health, social care and other practitioners about support for older people with learning disabilities to develop and maintain relationships with family, friends and the local community?
Quality of evidence	Recommendations 1.2.9, 1.2.11, 1.2.12, 1.2.13 and 1.2.14 are all based on evidence reviewed for question 6 about support for developing and maintaining connections with family and local communities. Nine papers were included in the review with only a small amount of moderate quality studies providing effectiveness data (n=3). Five studies provided data about the views and experiences of older people with learning disabilities and their families, carers and advocates. Their internal validity was moderate to good. Only 1 moderate quality study reported the views and experiences of practitioners. The issue of retirement was addressed in both effectiveness and views and experiences studies and there was also a small amount of effectiveness evidence about physical training programmes. There was only a small amount of data to improve understanding about access to transport and technology and this is reflected in the research recommendation on the role of technology. Recommendation 1.5.10 is based on evidence reviewed for question 3 about information, training and advice for older people with learning disabilities. A total of 6 papers were included for this question and overall, their internal validity was good to moderate. Only one effectiveness study was found, although the results were of limited use due to methods issues. The views and experiences or older people with learning disabilities and their families were well represented in the evidence but only one study provided the practitioner perspective. The views studies provided important information about what works and what does not in providing information. There was a particular lack of evidence trialling approaches or interventions, and a gap in evidence about

	training for older people with learning disabilities, whether it is needed and how best to provide it.
Economic considerations	No economic evidence was identified. The guideline committee thought that providing preventative services and support would reduce the demand for much more costly services and support currently provided by a wide range of public sector agencies including health and social care. In particular they thought that mainstream community services had an important role in providing access to preventative support, and that this was in the long-term the only cost-effective solution for this population considering the increasing number of people who live into old age.
Evidence statements – numbered evidence statements from which the recommendations were developed	R5: There is some evidence that older people with learning disabilities do not want to stop their daily activities – for example work or volunteering - after they reach retirement age. The quality of the evidence is mainly good. Analysis of the first wave of a longitudinal study in Ireland (McCarron et al. 2011 ++) found that older people with learning disabilities did not want to 'retire' from their day centre, which they felt they would have to do when they reached a certain age e.g. 50 years. They were particularly worried about losing relationships with staff and friends (p10). Similarly, a moderate quality Scottish study (Judge et al. 2010 +) found that older people with learning disabilities were very unhappy at the prospect of having to retire from their day centre at a certain age (in this case, 65 years) (p17). A good quality study (Newberry et al. 2015 ++) found that older people with learning disabilities wanted to continue working, learning or doing voluntary work even after retirement age (p20). (Recommendation 1.2.9) R8: There is a small amount of evidence that a mainstream community support group helps the transition to retirement for older people with learning disabilities. The quality of the evidence is moderate. An Australian study (Stancliffe et al. 2015 +) found that during retirement, a community support group increased the amount of contact that older people with learning disabilities experienced. It also resulted in them being happier with their social connections compared with people who had not attended the group (p4). (Recommendation 1.2.9) IAT6: There is a small amount of evidence about the effectiveness or cost effectiveness of training programmes or support for older people with learning disabilities. Puyenbroeck and Maes (2009 +) conducted a study to test a reminiscence program to improve the quality of life of older people with learning disabilities. Although participants enjoyed the session, the study found that people were just as happy with another programme, which did not include reminiscence. The design of the study also makes it difficult for us to have confidence in the findings (p1). (Recommendation 1.2.10) R7: There is some evidence that exercise programmes for older people with learning disabilities help improve wellbeing and reduce social isolation. The quality of the evidence is moderate. A moderate quality study conducted in Israel (Carmeli et al. 2008 +) found that a physical training programme for people with learning

	disabilities could improve their perception of well-being (in terms of social acceptance and physical appearance) and also reduce their sense of social isolation (p3). A moderate quality systematic review (Brooker et al. 2014 +) suggests that physical activity classes improve health and wellbeing among older people with learning disabilities and given there were social components to the programmes, also help create relationships (p1). (Recommendations 1.2.11 and 1.2.12) R4: The is a moderate amount of evidence that older people with learning disabilities want to be involved in activities which they define as useful or meaningful. The quality of the evidence is moderate to good. Analysis of the first wave of a longitudinal study in Ireland (McCarron et al. 2011 ++) found that older people with learning disabilities who did voluntary work, did so because they felt they were contributing something useful and it made them feel needed (p10). A moderate quality Scottish study (Judge et al. 2010 +) found that older people with learning disabilities were generally happy to be active but particularly happy when the activity helped someone else or contributed, for example to the running of the day centre (p17). A good quality study (Newberry et al. 2015 ++) found that older people with learning disabilities needed a sense of purpose and they wanted this to involve working, learning or voluntary work (p20). A moderate quality evaluation (Randell and Cumella 2009 +) found that in a specially designed living environment for people with learning disabilities, residents felt good because they saw themselves as a useful member of the community (p21). (Recommendation 1.2.13) R2: There is some evidence that older people with learning disabilities have poor access to independent transport, which restricts their ability to participate in social activities. The quality of the evidence is moderate to good. Analysis of the first wave of a longitudinal study in Ireland (McCarron et al. 2011 ++) found that the majority of respondents were dependent on others for transport and other assistance to access community activities (p10). Analysis of the second wave of the same study (IDSTILDA 2014 +) found that engagement in social activities declined when older people (mainly men) with learning disabilities were unable to travel around their local community (p9). (Recommendation 1.2.14)
Other considerations	Recommendation 1.2.9 is based on R5 and R8, which report evidence that older people with learning disabilities do not wish to stop their daily activities such as working or volunteering after they reach state retirement age. The evidence (in R8) also reports that a mainstream community support group helped older people with learning disabilities during the transition to retirement by ensuring they stay connected with others. The committee recognised that this transition period can be difficult and is compounded by the fact that older people with learning disabilities do not have the same choice when that others have to continue work. However they pointed out that it is not necessarily appropriate to focus on the concept of retirement for this group because many will have never worked and it may be a service that they have to leave at age 65 rather than a job. They agreed that it is more relevant to focus on ensuring that older people with

	learning disabilities have the opportunity to be engaged in activity, work, or volunteering, as they grow older, to the same extent that the non disabled population can. The committee agreed it is the responsibility of commissioners and service providers to ensure this equality of access. Recommendation 1.2.10 is based on IAT6 which reports just one study that found that older people with learning disabilities enjoyed a reminiscence group. The committee felt unable to specifically recommend reminiscence groups since the study findings were not convincing because the control group was just as happy with another programme, which did not involve reminiscence. Nevertheless the committee observed that the common thread of the 2 programmes was that the participants enjoyed was 'getting together'. They could see that meeting together and talking to other older people with learning disabilities could be helpful in improving people's wellbeing and the experts by experience endorsed this view. They therefore agreed to recommend that commissioners and providers ensure older people with learning disabilities have opportunities to socialise through clubs and groups. Recommendation 1.2.11 and 1.2.12 are based on R7 which reports evidence that exercise programmes for older people with learning disabilities help to improve wellbeing and reduce social isolation. The committee therefore agreed to recommend that commissioners and providers ensure a wide range of physical activity programmes are available to older people with learning disabilities and they provided a number of examples. They felt it was important not to just offer the person a list of things to do but instead, talk to them and find out what would interest and motivate them. Recommendation 1.2.13 is based on R4 which reports that older people with learning disabilities feel they need to be involved in activities they perceive to be meaningful. The committee agreed that people feel happier when they feel they are part of something or are contributing to something; involvement is key. Therefore they recommended that commissioners and providers have responsibility for arranging accessible opportunities for older people with learning disabilities to be involved in volunteering, work or education. Recommendation 1.2.14 is based on evidence from R2 that older people with learning disabilities lack access to independent transport, preventing them from engaging in social activities. The committee recognised this as a major barrier and therefore recommended that local authorities consider schemes to make transport easier for older people with learning disabilities. The committee drew on their own experience and expertise to provide examples of schemes that could be considered.

Topic/section heading	**Identifying and assessing care and support needs - assessing people's need for care and support**

Recommendations	1.3.1 Ensure that all assessments of care and support needs are person centred (NICE is publishing a guideline on people's experience in adult social care services in February 2018 which covers person-centred assessment). 1.3.2 Practitioners carrying out assessments of care and support needs should have: • access to the person's full history (medical, social, psychological and the nature of their learning disability) and • an understanding of their usual behaviour. 1.3.3 Practitioners carrying out assessments of care and support needs should be alert to any changes in the person's usual behaviour. This could include how they are communicating or their activity levels, and symptoms (such as weight loss, changes in sleeping patterns or low mood) that could show something is wrong or they are unwell. 1.3.4 When people have changing needs think about whether these changes could be age-related and do not assume they are due to the person's learning disability. 1.3.5 Practitioners conducting assessments of care and support needs should help people to think about what they want from life as they age. This should include: • asking people how they would like to spend their time and with whom • encouraging them to develop support networks and to build and maintain links with friends and family and with community groups – these might include social, cultural and faith-based groups.
Research recommendations	The Guideline Committee agreed the following research recommendations to address gaps in evidence about the identification of health conditions and the use of personalised technology to promote social relations: Research recommendation 2 What is the effectiveness and cost effectiveness of different ways of identifying age-related and other physical and mental health conditions, in older people with learning disabilities? What can mainstream and specialist health services do to facilitate: - early identification of health conditions in older people with learning disabilities? - equal access to health services in older people with learning disabilities? Research recommendation 6 What is the effectiveness and cost effectiveness of personal technology and social media to help older people with learning disabilities to maintain relationships with friends and family, build social contacts and access volunteering, social and leisure activities?

Review questions	1. What are the views and experiences of older people with learning disabilities and their carers about how care and support needs are identified, assessed and reviewed? 2. What are the views and experiences of health, social care and other practitioners about how the health and social care needs of older people with learning disabilities and their carers are identified, assessed and reviewed? 6a) What is the acceptability, effectiveness and cost effectiveness of care planning and support for older people with learning disabilities to access volunteering, employment and adult learning, social and leisure activities, transport and technology and maintain relationships with family, friends and within their local community? 6b) What are the views and experiences of older people and their carers in relation to support for developing and maintaining relationships with family, friends and the local community? 6c) What are the views and experiences of health, social care and other practitioners about support for older people with learning disabilities to develop and maintain relationships with family, friends and the local community?
Quality of evidence	Recommendations 1.3.1, 1.3.2, 1.3.3 and 1.3.4 are all based on discussions around the evidence included for review questions 1 and 2 about the identification, assessment and review of care and support needs among older people with learning disabilities. For question 1, there were 7 studies, which on average were moderate in terms of their internal validity. Only 1 study of moderate quality specifically answered question 2 and a further 4 studies provided data to answer both questions 1 and 2 because they reported practitioner views as well as views of older people with learning disabilities and their carers or families. There were gaps in the evidence about assessment and review of needs, with most of the data covering future planning. The gaps in the data led to discussions based on committee expertise, with crucial input from the experts by experience, including carers. Recommendation 1.3.5 is based on evidence reviewed for review question 6 about support for developing and maintaining connections with family and local communities. Nine papers were included in the review with only a small amount of moderate quality studies providing effectiveness data (n=3). Five studies provided data about the views and experiences of older people with learning disabilities and their families, carers and advocates. Their internal validity was moderate to good. Only 1 moderate quality study reported the views and experiences of practitioners. The issue of retirement was addressed in both effectiveness and views and experiences studies and there was also a small amount of effectiveness evidence about physical training programmes. There was only a small amount of data to improve understanding about access to transport and technology and this is reflected in the research recommendation on the role of technology.
Economic considerations	No economic evidence was identified. The guideline committee agreed that person-centred assessments could potentially require additional time from professionals but lead to important reduction

	in misdiagnosis, which was linked to repeat appointments and more intensive and costly treatment for health conditions when recognised at a late stage. The guideline committee reported that there were was strong evidence from the 2015 Public Health England study 'Prescribing of psychotropic drugs to people with disabilities and/or autism by general practitioners in England' that people were over-prescribed drugs for mental health conditions. They thought this evidence was very relevant for older people with learning disabilities and was also likely to concern drug prescriptions for other health conditions. The guideline committee thought that person-centred assessments would lead to a reduction in prescriptions, reducing costs, as well as improving health (avoiding the often substantial side effects of drugs).
Evidence statements – numbered evidence statements from which the recommendations were developed	IAR2: There is a moderate amount of evidence that families and practitioners fail to identify the needs of older people with learning disabilities because they wrongly attribute behaviours and symptoms. The quality of this evidence is moderate. A study by Bowers et al (2014 +) found that in a group home, delays in seeking care happened because symptoms were wrongly attributed to ageing, dementia or other existing conditions, without alternatives being explored. Another moderate (+) quality study found that services and families attributed behaviour changes in adults with a learning disability to Down syndrome rather than considering the onset of dementia (Carling-Jenkins et al, 2015). A low quality systematic review (Innes et al 2012 −) found that in generic ageing services changes experienced due to ageing were attributed to a person’s learning disability. Needs were therefore not identified. Finally, a UK study of paid care workers (Willis et al 2010 +) found they had difficulty separating signs and symptoms of the menopause from behaviours resulting from other causes. (Recommendations 1.3.2, 1.3.3 and 1.3.4) R6: There is some evidence that older people with learning disabilities feel powerless in relation to decisions about their activities and relationships. The quality of the evidence is mainly moderate. A moderate quality Scottish study (Judge et al. 2010 +) found that older people with learning disabilities were particularly distressed at the prospect of retiring because they felt the decision was out of their hands and they had no choice about it (p17). A good quality study (Newberry et al. 2015 ++) found that people with learning disabilities felt powerless as they grew older and were restricted from making their own decisions (p20). A moderate quality evaluation (Randell and Cumella, 2009 +) found that in a specially designed living environment for people with learning disabilities, residents felt good because they could participate in decision making (p21). (Recommendation 1.3.5) R1: There is some evidence that older people with learning disabilities who live in residential settings are less well connected with friends and their local community than people living in their family home. The quality of the evidence I moderate to good. Analysis of the first wave of a longitudinal study in Ireland (McCarron et al. 2011 ++) found that people in residential settings had less contact with their friends, were more likely to report loneliness and had more difficulty participating in activities outside the home (p10). Analysis of the second wave of the same study

	(IDSTILDA 2014 +) found that people living in community group and residential homes were more likely to experience social exclusion and less likely to be engaged in social activities than people living in the family home (p9). (Recommendation 1.3.5)
Other considerations	Recommendation 1.3.1 is based on evidence from IAR2 about the failure to identify comorbid conditions in older people with learning disabilities due to shortcomings in assessments. The committee therefore agreed that this recommendation should open the assessment section, ensuring that a person centred approach is taken to assessing care and support needs. Due to the overlap with the NICE guideline on people's experiences in adult social care services the committee wished to cross-refer to provide practitioners with greater detail about person centred assessments. Recommendations 1.3.2 and 1.3.3 are also based on evidence from IAR2. The guideline committee understood that the data described 'diagnostic overshadowing', which is highly prevalent in the context of older people with learning disabilities. Assessments of need or health often fail to recognise that a manifestation (physical or psychological) may be a sign that there is something else wrong because the person may be unable to communicate in the usual way. For example, dementia may be overlooked when people present with incontinence, which is simply attributed to the person's learning disability. In response to this, the committee developed 1.3.2 and 1.3.3 to ensure that practitioners conducting assessments have a thorough understanding of the person's history and should be alert to changes in behaviour, which may be an indication or symptom of illness. Recommendation 1.3.4 follows from this and is also based on IAR2. It emphasises that for this particular population it is extremely important to assess need in a way that acknowledges the ageing process and the difficulties and health issues that sometimes accompany it. When people's needs change, this should not be automatically attributed to their learning disability. : Recommendation 1.3.5 is based on R1 and R6 which provide data about the isolation that older people with learning disabilities often feel and how the changes experienced as they age (such as moving home or having to retire) exacerbate this problem. The group therefore agreed that older people with learning disabilities should be enabled to make decisions about the use of their time and that they should be encouraged to maintain existing networks and create new friendships. Although there was some reference to 'retirement' in the evidence (Judge et al. 2010 +) the committee agreed that it was more relevant to focus on life 'as people age' because retirement may not be something every older person with a learning disability experiences in the formal sense.

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Topic/section heading	**Assessing the needs of family members and carers**
Recommendations	1.36 Practitioners conducting assessments of care and support needs should take into account the needs, capabilities and

	wishes of families and carers. Also take into account that there may be mutual caring between older people with learning disabilities, and their family members and carers, who are likely to be older themselves and have their own support needs. 1.3.7 Practitioners must offer people who are caring for an older person with a learning disability their own carer's assessment, in line with the Care Act 2014. 1.3.8 Based on assessment, provide families and carers with support that meets their needs as carers. 1.3.9 Review the needs and circumstances of carers at least once a year and if something significant changes. 1.3.10 Actively encourage carers to register themselves as a carer, for example with their GP.
Research recommendations	The Guideline Committee agreed the following research recommendations to address gaps in evidence about the identification of health conditions and dementia training for families: Research recommendation 2 a) What is the effectiveness and cost effectiveness of different ways of identifying age-related and other physical and mental health conditions, in older people with learning disabilities? b) What can mainstream and specialist health services do to facilitate: - early identification of health conditions in older people with learning disabilities? - equal access to health services in older people with learning disabilities? Research recommendation 3 What is the effectiveness and cost effectiveness of education programmes to improve information and advice and to support self-management of chronic health conditions (for example obesity, diabetes and cardiovascular disease) for older people with learning disabilities and their family members and carers?
Review questions	1. What are the views and experiences of older people with learning disabilities and their carers about how care and support needs are identified, assessed and reviewed? 2. What are the views and experiences of health, social care and other practitioners about how the health and social care needs of older people with learning disabilities and their carers are identified, assessed and reviewed? 4 a) What is the acceptability, effectiveness and cost effectiveness of providing information, advice, training and support for families, carers and advocates of older people with learning disabilities? 4b) What are the views and experiences of older people with learning disabilities and their carers about information, advice, training and support provided to families, carers and advocates? 4c) What are the views and experiences of health, social care and other practitioners about information, advice, training and support for families, carers and advocates?

Quality of evidence	Recommendations 1.3.6, 1.3.7, 1.3.8 and 1.3.10 were all based on evidence reviewed for questions 1 and 2 about the identification, assessment and review of care and support needs among older people with learning disabilities. For question 1, there were 7 studies, which on average were moderate in terms of their internal validity. Only 1 study of moderate quality specifically answered question 2 and a further 4 studies provided data to answer both questions 1 and 2 because they reported practitioner views as well as views of older people with learning disabilities and their carers or families. There were gaps in the evidence about assessment and review of needs, with most of the data covering future planning. The gaps in the data led to discussions based on committee expertise, with crucial input from the experts by experience, including carers. Recommendation 1.3.9 was based on evidence reviewed for question 4 about information, training and advice for families, carers and advocates of older people with learning disabilities. Four papers were reviewed for question 4 and they provided data about the views and experiences of older people with learning disabilities and their families although no data on practitioner views. Overall, the internal validity of the studies was judged to be moderate. The studies focused on gaps in information, training and support needs for carers of older people. There was a lack of evidence trialling approaches or interventions, and gaps in evidence about training programmes for older people with learning disabilities, in terms of how best to provide them and how effective they are.
Economic considerations	No economic evidence was available to inform the recommendations. It was expected that principles of the recommendations around assessments that include families and carers could be implemented without substantial costs. In addition, any additional costs of assessment following the recommendations were thought to save additional time later on because information did not have to be revisited unnecessarily, the number of repeat appointments could be reduced, and negative long-term consequences could be avoided. Specific examples of potentially preventable impact have been considered under other recommendations.
Evidence statements – numbered evidence statements from which the recommendations were developed	IAR4: There is a moderate amount of evidence that despite reported anxiety about the future, families of adults with learning disabilities do not carry out future planning. The quality of the evidence is mixed. The majority of participants in Dillenberger and McKerr (2011 +) had not discussed future provision of care and support with social services and avoided discussion within their families at the risk of causing distress. Similarly only a minority of parents in another study (Towers 2013 −) had spoken to practitioners about future planning. Families with relatives in group homes had clearly not considered future planning (Bigby et al. 2011 ++) and in Innes et al. (2012 −) families and supporters were unwilling or unable to undertake forward planning. (Recommendations 1.3.6, 1.3.7, 1.3.8 and 1.3.10) FCA3: There is a small amount of evidence that support needs for families and carers of older people with learning disabilities and dementia are not being met. The quality of the evidence is

	moderate. The study by Atkins and Loverseed (2012 +) reported that some family carers were reluctant to ask for formal support because of past negative experiences with professionals and services (p1). The UK study by McLaughlin and Jones (2011 +) found that carers' support needs increased after the older person with a learning disability had been diagnosed with dementia, for example because of the increase in medical appointments. Families and carers needed to access respite services but did not know how (p5). The American study by Janicki et al. (2010 +) also found that carers had unmet needs from respite services (p4). (Recommendation 1.3.9)
Other considerations	Recommendation 1.3.6, 1.3.7, 1.3.8 and 1.3.10 are all based on evidence from IAR4, which reports a lack of future planning around the care and support needs of older people with learning disabilities, despite substantial anxiety about the future among parents and other family members. Reasons why planning had not occurred reportedly included a lack of support by practitioners and an unwillingness among family members to focus on distressing matters such as the death of parents and the impact on older person with a learning disability. Acknowledging the interrelatedness of families, the committee therefore developed 1.3.6 to ensure that when people's support needs are being assessed, practitioners should take account of families' and carers' wishes and abilities to contribute to supporting that person. They developed 1.3.7 to alert practitioners to their legal duty to offer an assessment to people caring for a family member or friend and 1.3.8 to ensure that carers' established needs should be supported. Recommendation 1.3.9 is based on FCA3, which reports that families' and carers' support needs are not in fact being met. This is brought into particular focus at points such as a dementia diagnosis when families felt their own support needs increased. The committee therefore agreed that after the initial assessment of their needs (as in 1.3.8), carers' should have further assessments and reviews on an annual basis or when circumstances change Recommendation 1.3.10 is also based on IAR4 and it represents the need, agreed by the guideline committee, for carers of older people with learning disabilities to be known to commissioners and providers so that their needs can be better supported.

Topic/section heading	**Planning and reviewing care and support - person-centred planning and review**
Recommendations	1.4.1 Practitioners should carry out regular person-centred planning with people who have a learning disability to address their changing needs, wants and capabilities. This includes planning for the future. Involve their family, carers and advocates as appropriate. 1.4.2 Include transport needs in people's care and support plans, to help them get to services, appointments and activities. 1.4.3 Local authorities should plan people's care and support in

	a way that meets the needs of all family members, as well as the older person with a learning disability. This might include combining the personal budgets of different family members. 1.4.4 Give families and carers, including siblings, help in planning and providing support for the older person with a learning disability. For example, signposting people to resources about how to support people after a family bereavement.
Research recommendations	The Guideline Committee agreed the following research recommendation to address gaps in evidence about the identification of health conditions and dementia training for families: Research recommendation 2 a) What is the effectiveness and cost effectiveness of different ways of identifying age-related and other physical and mental health conditions, in older people with learning disabilities? b) What can mainstream and specialist health services do to facilitate: - early identification of health conditions in older people with learning disabilities? - equal access to health services in older people with learning disabilities? Research recommendation 4 What is the effectiveness, cost effectiveness and acceptability of training programmes (for example in the use of life story work) for families of older people with learning disabilities who have dementia or are at risk of developing it?
Review questions	4a) What is the acceptability, effectiveness and cost effectiveness of providing information, advice, training and support for families, carers and advocates of older people with learning disabilities? 4b) What are the views and experiences of older people with learning disabilities and their carers about information, advice, training and support provided to families, carers and advocates? 4c) What are the views and experiences of health, social care and other practitioners about information, advice, training and support for families, carers and advocates? 5a) What is the acceptability, effectiveness and cost effectiveness of interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 5b) What are the views and experiences of older people with learning disabilities and their carers about interventions or approaches to improve access and referral to health, social care and housing support services? 5c) What are the views and experiences of health, social care and other practitioners about interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 9a) What are the views and experiences of older people with learning disabilities and their carers about care and support in health settings?

	9b) What are the views and experiences of health, social care and other practitioners about the care and support of older people with learning disabilities in health settings?
Quality of evidence	Recommendation 1.4.1 is based on evidence for review question 9 about care and support for older people with learning disabilities in health settings. Overall, for question 9, 6 studies were located and they were moderate to good in terms of internal validity. Practitioner, service user and family views were all represented, providing useful insight into the experiences and preferences of older people with learning disabilities in relation to health assessments and interaction with practitioners although there were clear gaps in evidence about the perspective of health practitioners e.g. hospital practitioners or GPs. Recommendation 1.4.2 is based on evidence for review question 5 about access and referral to health, social care and housing services. The evidence located for review question 5 (n=7) was moderate to good in terms of internal validity and provided data on the views and experiences of older people with learning disabilities, their families and carers and also of practitioners. There was no effectiveness evidence and the views and experiences data focussed on barriers to access rather than means of improving access and referral. Recommendation 1.4.3 is based on expert testimony about support in the home for older people with learning disabilities. Recommendation 1.4.4 is based on evidence for review question 4 about information, training and advice for families, carers and advocates of older people with learning disabilities. Four papers were reviewed for question 4 and they provided data about the views and experiences of older people with learning disabilities and their families although no data on practitioner views. Overall, the internal validity of the studies was judged to be moderate. The studies focused on gaps in information, training and support needs for carers of older people. There was a lack of evidence trialling approaches or interventions, and gaps in evidence about training programmes for older people with learning disabilities, in terms of how best to provide them and how effective they are.
Economic considerations	No economic evidence was identified. These recommendations refer to the principles of care planning and review and more specific recommendations are made in other sections, in particular on health and housing. Economic considerations are discussed in more detail for those specific examples. Overall, the Guideline Committee agreed that person-centred planning was important in order to identify and address problems early on. This could help to prevent the costs linked to more intensive treatment and support, and the cost of crisis. Involving the family was considered particularly important; an example of the costly consequences if families were not included in the care planning and review was linked to the higher risk that relationships broke down without involving families and the person would have to move out. The Guideline Committee also discussed the important role of mainstream health, social care and housing support services in being able to provide care for this population, which would be less costly than providing specialist services. They

	thought that in the long-term, a system of specialist services was financially unstainable as it would need to meet the increasing demand linked to this ageing population; adjustments in mainstream services were the more affordable solution to provide care and support for this population.
Evidence statements – numbered evidence statements from which the recommendations were developed	HS4: There is a small amount of evidence that people's experiences of health check-ups or assessments are markedly improved when they are given clear explanations about what to expect. The quality of the evidence is good. A study by Truesdale-Kennedy et al. (2011 ++) reported that women with learning disabilities felt that breast screening would be far less frightening if they were provided with accessible information and given clear explanations about what to expect before the examination (p6). A study by Webber (2010 ++) found that carers were concerned about the failure of hospital practitioners to describe treatment and diagnosis to older people with learning disabilities on the assumption that they would not understand (p8). (Recommendation 1.4.1) AR3: There is a moderate amount of evidence that older people with learning disabilities have limited access to support because of a lack of services designed specifically to address their needs and preferences. The quality of the evidence is mostly moderate. Wark et al. (2015 ++) found that in rural Australia, older people with learning disabilities had to travel very long distances from home in order to access specialist health services. In addition, where learning disability services were available locally, access was limited by having few, if any, options (p5). Benbow et al. (2011 +) reported that learning disability practitioners said psychiatry services for older people in the UK specifically exclude people with learning disabilities (p8). The US study by Coyle (2016 +) reported clear difficulties from a practitioner perspective around being able to provide resources and support to older people with learning disabilities. As a result staff admitted to not addressing the needs of the specific population in the provision of services although it was something they recognized they ought to in future (p9). Finally, a study conducted in Ireland (Dodd et al. 2009 +) found that one of the reasons older adults with learning disabilities did not access specialist learning disability services was that families judged that they were not appropriate to meet the person's needs (p12). (Recommendation 1.4.2) FCA1: There is a small amount of evidence that families of older people with learning disabilities are not given the support and information needed to take an active role in planning. The quality of the evidence is moderate. A UK study by Atkins and Loverseed (2012 +) found that some carers felt excluded from care planning and this was attributed to not being sufficiently well informed about the older person's health condition (p1). Another UK study by Tozer and Atkin (2015 +) found that siblings of older people with learning disabilities wanted to take on more responsibilities in future and wanted support from professionals to do this. They felt that in general, professionals were not proactive in involving them in future planning (p8). (Recommendation 1.4.4)

Other considerations	Recommendation 1.4.1 is based on discussions about HS4 which presented evidence that older people with learning disabilities have a better experience of health checks if they receive detailed explanations throughout. The group therefore agreed this recommendation for on-going planning and identification of needs, which involves clear explanations. The committee also agreed about the importance of including families in this planning. Recommendation 1.4.2 is based on evidence from AR3 about a lack of transport being a key barrier preventing older people with learning disabilities from accessing support. Recommendation 1.4.3 is based on expert testimony about support in the home for older people with learning disabilities. Recommendation 1.4.4 is based on evidence from FCA1 about families and carers having insufficient information and resources to be able to fully support the older person with a learning disability. In particular siblings felt that although they wanted to take on more responsibility for providing support, they needed help from practitioners to do so. Therefore the guideline committee agreed that families, including siblings should be given the resources they need to help their relative. The experts by experience said that this might include the provision of support when parents die so it was felt particularly important to emphasise that the non-disabled sibling should be helped to do this.

Topic/section heading	**Planning and reviewing care and support - planning for the future**
Recommendations	1.4.5 Health and social care practitioners should work with the person and those most involved in their support to agree a plan for the person's future. Help them to make decisions before a crisis point or life-changing event is reached (for example, the death of a parent or a move to new housing). 1.4.6 Planning for the future should: • be proactive • be led by the person themselves with input from family members, carers and advocates as appropriate

	(regardless of whether they provide care and support themselves) • involve a practitioner who has a good relationship with the person and communicates well with them • involve practitioners who have good knowledge of local resources • take into account the whole of the person's life, including their hopes and dreams as well as the things they do not want to happen • include considering the needs of family members and carers • seek to maintain the person's current support and housing arrangements, if this is their preference • be reviewed every year and whenever the person's needs or circumstances change. 1.4.7 Include as key components of a future plan: • Housing needs and potential solutions. • Any home adaptations or technology that may address people's changing needs as they grow older. • Members of the person's support network (both paid and unpaid). • Any help the person gives to other family members, whether this will continue as they age, and the impact this may have on their health and wellbeing. • Financial and legal issues, for example whether someone has been appointed to have lasting power of attorney for the person. • Planning for unexpected changes or emergencies. • Consideration of deprivation of liberty safeguards, for instance if planned changes to care or the care environment are likely to increase restrictions on the person. • End of life care decisions – including where the person wants to be when they die. These decisions should be reviewed at least once a year.
Research recommendations	The Guideline Committee agreed the following research recommendations to address gaps in evidence about the identification of health conditions, dementia training for families, advance planning for end of life care and care and support at the end of life: Research recommendation 2 a) What is the effectiveness and cost effectiveness of different ways of identifying age-related and other physical and mental health conditions, in older people with learning disabilities? b) What can mainstream and specialist health services do to facilitate: - early identification of health conditions in older people with learning disabilities?

	- equal access to health services in older people with learning disabilities? Research recommendation 4 What is the effectiveness, cost effectiveness and acceptability of training programmes (for example in the use of life story work) for families of older people with learning disabilities who have dementia or are at risk of developing it? Research 5 a) What is the effectiveness and cost effectiveness of advance care planning about end of life care for older people with learning disabilities, and their family members and carers? b) What processes are in place to document and follow the wishes of older people with learning disabilities about their decisions on end of life care? Research recommendation 8 a) What is the effectiveness and cost effectiveness of end of life care for older people with learning disabilities? b) What can mainstream health and social care services do to support older people with learning disabilities and their primary carer (both family and paid carers) at the end of life?
Review questions	1. What are the views and experiences of older people with learning disabilities and their carers about how care and support needs are identified, assessed and reviewed? 2. What are the views and experiences of health, social care and other practitioners about how the health and social care needs of older people with learning disabilities and their carers are identified, assessed and reviewed? 4a) What is the acceptability, effectiveness and cost effectiveness of providing information, advice, training and support for families, carers and advocates of older people with learning disabilities? 4b) What are the views and experiences of older people with learning disabilities and their carers about information, advice, training and support provided to families, carers and advocates? 4c) What are the views and experiences of health, social care and other practitioners about information, advice, training and support for families, carers and advocates? 8a) What is the effectiveness and cost effectiveness of end of life care for older people with learning disabilities? 8b) What are the views and experiences of older people with learning disabilities and their carers in relation to end of life care? 8c) What are the views and experiences of health, social care and other practitioners about support for older people with learning disabilities at the end of life?
Quality of evidence	Recommendations 1.4.5, 1.4.6 and 1.4.7 are all based on evidence reviewed for review questions 1 and 2 about the identification, assessment and review of care and support needs among older people with learning disabilities. For question 1, there were 7 studies, which on average were moderate in terms of their internal validity. Only 1 study of moderate quality specifically answered question 2 and a further 4 studies provided

	data to answer both questions 1 and 2 because they reported practitioner views as well as views of older people with learning disabilities and their carers or families. There were gaps in the evidence about assessment and review of needs, with most of the data covering future planning. The gaps in the data led to discussions based on committee expertise, with crucial input from the experts by experience, including carers. Recommendation 1.4.6 is also supported by evidence reviewed for question 4 about information, training and advice for families, carers and advocates of older people with learning disabilities. Four papers were reviewed for question 4 and they provided data about the views and experiences of older people with learning disabilities and their families although no data on practitioner views. Overall, the internal validity of the studies was judged to be moderate. The studies focused on gaps in information, training and support needs for carers of older people. There was a lack of evidence trialling approaches or interventions, and gaps in evidence about training programmes for older people with learning disabilities, in terms of how best to provide them and how effective they are. Recommendation 1.4.7 is also supported by evidence reviewed for question 8 about end of life care, which included 11 papers. There was limited evidence about the views and experiences of older people with learning disabilities and their families (n=2) and no effectiveness or cost-effectiveness evidence. The 9 studies providing practitioner views were low to moderate in terms of internal validity.
Economic considerations	No economic evidence was identified. The Guideline Committee discussed the economic consequences if future planning was not done. This included possible relationship breakdown and the person having to move out. If future planning did not take place, it was more likely that more expensive (housing) crisis and emergency care and arrangements were required. The Guideline Committee also discussed the negative mental health outcomes for the person and their family when future planning did not take place. This was linked to worries and stress about whether the person would be able to live where they were happy. The costs of a person being placed away from home were also discussed. This included the costs of out-of-pocket expenditure for travelling if the person was placed far away from home. It was thought that future planning could prevent some of those negative cost consequences.
Evidence statements – numbered evidence statements from which the recommendations were developed	IAR5: There is some evidence that future housing needs are a key worry for adults with learning disabilities and their families. Overall the quality of the evidence is moderate. In the low quality Towers study (2013 −) over 80% of parents were extremely worried or worried about whether, in the future, their son or daughter would have a place to live where they were happy. Ageing adults with learning disabilities were also reportedly worried about their future living arrangements (Hole et al. 2013 ++). In a moderate quality study, despite the stress of thinking about a future without their parents, ageing adults with a learning disability had clear preferences for their future housing. The availability of local support and remaining in their local area were

	high priorities (Bowey and McGlaughlin 2005 +). Finally, according to Innes et al. (2012 −) practitioners and families were worried about the prospect of independent living for the adult with a learning disability because they felt there were associated risks. (Recommendation 1.4.5) IAR3: There is a moderate amount of evidence that older people with learning disabilities and their families are fearful about the future especially in terms of accommodation, finances, declining health and the provision of care and support. The quality of the evidence is mixed. One study by Towers (2013 −) and another by Innes et al (2012 −) reported high levels of anxiety and fear among parents, particularly around future care and support. A good quality study by Hole et al (2013 ++) found that adults with learning disabilities were worried about their own future, including being lonely and also about their ageing parents. Family members were anxious about the future financial security of the adult with a learning disability and their ability to make their own choices. Two studies (Bowey and McGlaughlin 2005 +, Dillenburger and McKerr 2011 +) specifically reported panic among adults with learning disabilities when they contemplated their parents' or carers' ill health and death. (Recommendations 1.4.6 and 1.4.7) FCA1: There is a small amount of evidence that families of older people with learning disabilities are not given the support and information needed to take an active role in planning. The quality of the evidence is moderate. A UK study by Atkins and Loverseed (2012 +) found that some carers felt excluded from care planning and this was attributed to not being sufficiently well informed about the older person's health condition (p1). Another UK study by Tozer and Atkin (2015 +) found that siblings of older people with learning disabilities wanted to take on more responsibilities in future and wanted support from professionals to do this. They felt that in general, professionals were not proactive in involving them in future planning (p8). (Recommendation 1.4.6) IAR6: There is some evidence that planning for the future of older people with learning disabilities should involve the whole family, including the person themselves. A moderate quality study by Coyle et al (2014 +) highlighted the importance of future planning with regard to the sibling role. Siblings said they needed to plan for a situation in which their parents could no longer provide care. Where parents had made future plans, a moderate quality study (Dillenburger and McKerr 2011 +) reported that they involved transferring the family home and caring responsibilities to non-learning-disabled children. On the other hand parents interviewed in a good quality study (Hole et al. 2013 ++) said they did not want their other children to be "burdened" with caring for their sibling. The results of this study point to the importance of early planning that balances the needs and desires of ageing adults with learning disabilities and family members. Finally, Bowey and McGlaughlin (2005 +) found that in situations of 'mutual caring', adults with learning disabilities were reluctant to move away to shared accommodation out of concern for how their parents will cope. This highlights that the line between carer and cared for is

	often blurred and everyone's wishes and needs must be considered during future planning. (Recommendation 1.4.6) IAR4: There is a moderate amount of evidence that despite reported anxiety about the future, families of adults with learning disabilities do not carry out future planning. The quality of the evidence is mixed. The majority of participants in Dillenberger and McKerr (2011 +) had not discussed future provision of care and support with social services and avoided discussion within their families at the risk of causing distress. Similarly only a minority of parents in another study (Towers 2013 −) had spoken to practitioners about future planning. Families with relatives in group homes had clearly not considered future planning (Bigby et al. 2011 ++) and in Innes et al. (2012 −) families and supporters were unwilling or unable to undertake forward planning. (Recommendation 1.4.6) EL5: There is some evidence about the importance of person centred care for people with learning disabilities at the end of their lives. The quality of the evidence is moderate. McCarron (2010 +) found that disability service staff felt that knowing the person's likes/ dislikes were seen as being central to good dementia care. Respondents felt that learning disability services have a strong philosophy of person centred care. Morton-Nance (2012 +) found that community nurses reported positive experiences when palliative care was person centred and included good planning, preparation, outreaching and sharing of information with other healthcare professionals. Cartlidge (2010 −) reported that staff felt it was very important to get to know people with learning disabilities and to build up trust and confidence when caring for them at the end of their lives. (Recommendation 1.4.7)
Other considerations	Recommendation 1.4.5 is based on IAR5 about the anxiety felt by parents when they considered where their son or daughter with a learning disability would live when they were older and when they (the parents) were dead. The guideline committee agreed that in order to address this, health and social care practitioner should work the person and those involved in their support to plan for the future before a crisis point is reached. Recommendation 1.4.6 was developed on the basis of FCA1, IAR3, IAR4 and IAR6 about the anxiety surrounding future support for older people with learning disabilities, the lack of future planning and the perceived barriers to future planning. The guideline committee originally developed a number of individual recommendations about how future planning should be conducted but they subsequently agreed to amalgamate them into a single recommendation providing a checklist for practitioners. One of the issues the committee debated was whether despite the evidence mainly pertaining to people living in the family home, this approach to future should actually be taken for all older people with learning disabilities. The group agreed that it should, hence referring to maintaining 'the person's current support and accommodation arrangements', whatever they may be. All the elements of this recommendation are equally important as a means of ensuring well coordinated person centred future planning, which involves families and

	knowledgeable practitioners and is reviewed whenever the person's needs or circumstances change. Recommendation 1.4.7 is based on evidence reported in IAR3 about anxiety among older people and their families in relation to future care and support. It is also based on evidence from EL5 about the importance of person centred end of life care planning and preparation. Originally the guideline committee drafted a number of separate recommendations about what should be covered in a future plan but they decided to amalgamate them into one recommendation providing a checklist for practitioners about the key components of future planning. Most of the components reflect shortcomings in future planning as described by the evidence. However others – such as home adaptations and deprivation of liberty safeguards - were identified by the committee themselves from their own experiences about the components that should be considered as a means of supporting and safeguarding the person as they age

Topic/section heading	**Planning and reviewing care and support - future housing**
Recommendations	1.4.8 When helping the person plan where they will live in the future and who they will live with, take into account whether other family members rely on them for support. 1.4.9 Encourage and support people to be active and independent at home regardless of their age or disability. This might include doing household tasks, making their own decisions and plans or leading group activities. 1.4.10 Make reasonable adjustments to people's homes as they grow older to make it possible for them to stay in their current home if they want to. For example, consider a support phone line, daily living equipment, telehealth monitoring and home adaptations, such as shower room conversion, wider doorways or a lift between floors. 1.4.11 Review the housing needs of people who are being supported by social care staff at home at least once a year. 1.4.12 Ensure that an advocate or, if appropriate, a family member or carer is centrally involved in decisions about whether a person should move from supported living to residential care. 1.4.13 If a move into residential care is agreed with the person, practitioners should work with them and their support network to start planning for this straightaway. Planning could include: • arranging for the person to visit the residential setting • discussing how they will maintain their existing support networks and develop new ones.
Research recommendations	The Guideline Committee agreed the following research recommendations to address gaps in evidence about the identification of health conditions, the use of personalised technology to promote social relations, care and support at home, and tele-monitoring: Research recommendation 1

	What is the effectiveness and cost effectiveness of care and support models (for example, assistive technology) for older people with learning disabilities to enable them to live at home with or without their family? Research recommendation 2 a) What is the effectiveness and cost effectiveness of different ways of identifying age-related and other physical and mental health conditions, in older people with learning disabilities? b) What can mainstream and specialist health services do to facilitate: - early identification of health conditions in older people with learning disabilities? - equal access to health services in older people with learning disabilities? Research recommendation 6 What is the effectiveness and cost effectiveness of personal technology and social media to help older people with learning disabilities to maintain relationships with friends and family, build social contacts and access volunteering, social and leisure activities? Research recommendation 7 a) What is the effectiveness and cost effectiveness of telemonitoring for older people with learning disabilities in: - promoting understanding and improving management of chronic physical and mental health conditions? - supporting their ageing family carers to continue providing care?
Review questions	1. What are the views and experiences of older people with learning disabilities and their carers about how care and support needs are identified, assessed and reviewed? 2. What are the views and experiences of health, social care and other practitioners about how the health and social care needs of older people with learning disabilities and their carers are identified, assessed and reviewed? 6a) What is the acceptability, effectiveness and cost effectiveness of care planning and support for older people with learning disabilities to access volunteering, employment and adult learning, social and leisure activities, transport and technology and maintain relationships with family, friends and within their local community? 6b) What are the views and experiences of older people and their carers in relation to support for developing and maintaining relationships with family, friends and the local community? 6c) What are the views and experiences of health, social care and other practitioners about support for older people with learning disabilities to develop and maintain relationships with family, friends and the local community? 7a) What is the acceptability, effectiveness and cost effectiveness of care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities?

	7b) What are the views and experiences of people using services and their carers in relation to care at home, in supported housing or accommodation with care and support for older people with learning disabilities? 7c) What are the views and experiences of health, social care and other practitioners about care and support at home, in supported housing or accommodation with care and support for older people with learning disabilities?
Quality of evidence	Recommendation 1.4.8 is based on evidence from review questions 1 and 2 about the identification, assessment and review of care and support needs among older people with learning disabilities. For question 1, there were 7 studies, which on average were moderate in terms of their internal validity. Only 1 study of moderate quality specifically answered question 2 and a further 4 studies provided data to answer both questions 1 and 2 because they reported practitioner views as well as views of older people with learning disabilities and their carers or families. There were gaps in the evidence about assessment and review of needs, with most of the data covering future planning. The gaps in the data led to discussions based on committee expertise, with crucial input from the experts by experience, including carers. Recommendation 1.4.9 is based on evidence from question 6 about support for developing and maintaining connections with family and local communities. Nine papers were included in the review with only a small amount of moderate quality studies providing effectiveness data (n=3). Five studies provided data about the views and experiences of older people with learning disabilities and their families, carers and advocates. Their internal validity was moderate to good. Only 1 moderate quality study reported the views and experiences of practitioners. The issue of retirement was addressed in both effectiveness and views and experiences studies and there was also a small amount of effectiveness evidence about physical training programmes. There was only a small amount of data to improve understanding about access to transport and technology and this is reflected in the research recommendation on the role of technology. Recommendation 1.4.10, 1.4.11 and 1.4.13 are all based on evidence from question 7 about care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities. A total of 8 papers were reviewed for this question although there was very little effectiveness evidence, with data found in just 1 study. Data on views and experiences were mainly from the practitioner perspective (n=5), on supporting adults with learning disabilities in group homes as they grow older and supporting adults with learning disabilities in residential care for older people. There were gaps in evidence about the effectiveness and experiences of care and support in the family home, which had implications for developing recommendations and drawing on other evidence, in particular expert testimony. Recommendation 1.4.13 is based on evidence from review questions 1 and 2, the quality of which is described above.

Economic considerations	No economic evidence was identified. The guideline committee agreed that providing support so that the person could stay at their home was a key priority. The guideline committee agreed that the person was likely to live with better mental health if they could stay in their own home. They thought that taking away the current support network could have a detrimental impact on the person's mental and general health causing further deterioration, social isolation and greater health and social care needs. Whilst the guideline committee recognised that providing the appropriate care package (including in form of adaptations) might be linked to additional costs, they thought that this was extremely important. They also thought that on average this was less costly than paying for the alternative, which usually involved large government expenditures for paying nursing home or residential care for the person with learning disability as well as potentially another family member (if the person was caring for someone). Another important consideration was also that placements were often in a different catchment requiring carers and family members to travel long distances, which could cause substantial problems including financial ones.
Evidence statements – numbered evidence statements from which the recommendations were developed	IAR6: There is some evidence that planning for the future of older people with learning disabilities should involve the whole family, including the person themselves. A moderate quality study by Coyle et al (2014 +) highlighted the importance of future planning with regard to the sibling role. Siblings said they needed to plan for a situation in which their parents could no longer provide care. Where parents had made future plans, a moderate quality study (Dillenberger and McKerr 2011 +) reported that they involved transferring the family home and caring responsibilities to non-learning-disabled children. On the other hand parents interviewed in a good quality study (Hole et al. 2013 ++) said they did not want their other children to be “burdened” with caring for their sibling. The results of this study point to the importance of early planning that balances the needs and desires of ageing adults with learning disabilities and family members. Finally, Bowey and McGlaughlin (2005 +) found that in situations of ‘mutual caring’, adults with learning disabilities were reluctant to move away to shared accommodation out of concern for how their parents will cope. This highlights that the line between carer and cared for is often blurred and everyone’s wishes and needs must be considered during future planning. (Recommendation 1.4.8) R4: The is a moderate amount of evidence that older people with learning disabilities want to be involved in activities which they define as useful or meaningful. The quality of the evidence is moderate to good. Analysis of the first wave of a longitudinal study in Ireland (McCarron et al. 2011 ++) found that older people with learning disabilities who did voluntary work, did so because they felt they were contributing something useful and it made them feel needed (p10). A moderate quality Scottish study (Judge et al. 2010 +) found that older people with learning disabilities were generally happy to be active but particularly happy when the activity helped someone else or contributed, for example to the running of the day centre (p17). A good quality study (Newberry et al. 2015 ++) found that older people with learning disabilities

	needed a sense of purpose and they wanted this to involve working, learning or voluntary work (p20).A moderate quality evaluation (Randell and Cumella 2009 +) found that in a specially designed living environment for people with learning disabilities, residents felt good because they saw themselves as a useful member of the community (p21). (Recommendation 1.4.9) H6: There is some evidence that adults with learning disabilities move to care homes generally because the home environment in which they had been living can no longer meet their needs. The quality of that evidence is moderate. Bigby's (2008 +) survey findings showed that most older adults had moved to care homes from the family home because their carer had died or was in hospital. Where they had moved to a care home from another residential setting, it was due to the inability of that facility to provide adequate specialist support (p7). The group home supervisors in Webber et al. (2010 +) said the most frequent reasons people moved into residential care were physical conditions, losing stamina and cognitive problems. Almost all agreed there would come a point when all residents would require more intensive or skilled care than they could provide and would therefore have to move to residential care (p17). Similarly, group home staff in Iacono et al. (2014 ++) admitted that although it was against their better judgement, residents would inevitably have to move to care homes because they lacked the skills to provide specialist support (p10). (Recommendations 1.4.10, 1.4.11 and 1.4.12) IAR1: There is a small of good quality evidence that practitioners supporting adults with learning disabilities feel they cannot continue to provide care throughout the person's 'old' age. One good quality study (Bigby et al. 2011 ++) found that when a person's medical or personal care needs reached a certain level they would have to move to an aged care environment. The point at which their needs reached this level was subjective and variable and it was hard for families to anticipate. (Recommendation 1.4.13)
Other considerations	Recommendation 1.4.8 is based on evidence reported in IAR6 that adults with learning disabilities in 'mutual caring' situations, were often reluctant to move into shared accommodation out of concern for how their patents will cope. This evidence was rated as moderate quality and it resonated with the committee's experience of mutual caring situations and the significance for future planning. They therefore agreed a recommendation to try and ensure that discussions about future housing changes take into account possible adverse effects on the family. Recommendation 1.4.9 is based on evidence in R4 about the importance that older people with learning disabilities attach to meaningful involvement in activities or jobs. The guideline committee therefore agreed to recommend that in the context of future planning, care should be taken to encourage ongoing and active involvement in household tasks or roles. This also reflects the strengths based approach promoted in the Care Act. Recommendation 1.4.10 is based on H6, which reports moderate quality evidence that older people with learning disabilities move

	into care homes because their current housing or support fails to meet their changing needs. The guideline committee felt that as with the general population, every effort should be made to ensure that people can stay in their current home if that is what they want. The committee made suggestions based on their own expertise, about the kind of adjustments that should be considered, although it should be noted this is not an exhaustive list, simply a means of providing examples. Recommendation 1.4.11 is also based on H6, particularly the evidence about a lack of appropriate support in group homes resulting in older people with learning disabilities moving to residential care. Although the evidence focussed on people living in group homes, committee members were determined that housing needs should be reviewed at least once a year for all older people with learning disabilities living at ‘home’, whether that home is a group home or the family home. Recommendation 1.4.12 is also based on H6, particularly the evidence about the role of managers in supported living environments who decided that the person’s needs had escalated beyond a point that could be managed within current arrangements. The committee agreed that managers usually have the final say on when someone needs to move to a care-home. They were concerned that managers may misinterpret medication side effects or other temporary symptoms as something more serious or permanent like a dementia and make the wrong decision about the person’s future. Therefore the committee agreed a recommendation to ensure that the older person themselves and if appropriate a family member, should be involved in decisions about whether a person should move from into a care home. Recommendation 1.4.13 is based on IAR1 which reports evidence that practitioners supporting adults with learning disabilities feel they cannot continue to provide adequate support as the person ages and their needs increase. The committee felt strongly that this situation should be anticipated and planned for and that the older person themselves should be helped to prepare by planning early, including about how they can continue friendships developed in their current home environment.

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Topic/section heading	**Identifying and managing health needs**
Recommendations	1.5.1 Healthcare practitioners should encourage older people with learning disabilities to choose a family member or carer to bring with them to medical examinations and appointments if they would like this support. 1.5.2 Explain clearly to older people with learning disabilities what will happen during any medical appointments as well as their likely follow-up care. In line with the Mental Capacity Act 2005, healthcare practitioners must take all reasonable steps to help the person understand this explanation.

	1.5.3 As well as explaining to people beforehand what will happen, continue to explain what is happening throughout the appointment and ensure there is enough time set aside to do this. If the person agrees, also explain to their family members and carers what will happen. 1.5.4 If the person needs a medical examination give them a choice, wherever possible, about where it takes place. Aim to do it in a place that is familiar to them, which is welcoming and appropriate to their needs. 1.5.5 Support family members and carers, for example by providing information, to enable older people with learning disabilities to access health services. 1.5.6 Consider training for people and their family members and carers in recognising and managing age-related conditions such as: • hearing loss and sight problems • blood pressure and cholesterol • prostate cancer • epilepsy • diabetes • osteoporosis • thyroid problems • menopausal symptoms • mental health, including depression and dementia.
Research recommendations	The Guideline Committee agreed the following research recommendations to address gaps in evidence about the identification of health conditions and dementia training for families: Research recommendation 2 a) What is the effectiveness and cost effectiveness of different ways of identifying age-related and other physical and mental health conditions, in older people with learning disabilities? b) What can mainstream and specialist health services do to facilitate: - early identification of health conditions in older people with learning disabilities? - equal access to health services in older people with learning disabilities? Research recommendation 4 What is the effectiveness, cost effectiveness and acceptability of training programmes (for example in the use of life story work) for families of older people with learning disabilities who have dementia or are at risk of developing it?
Review questions	4a) What is the acceptability, effectiveness and cost effectiveness of providing information, advice, training and support for families, carers and advocates of older people with learning disabilities? 4b) What are the views and experiences of older people with learning disabilities and their carers about information, advice, training and support provided to families, carers and advocates?

	4c) What are the views and experiences of health, social care and other practitioners about information, advice, training and support for families, carers and advocates? 5a) What is the acceptability, effectiveness and cost effectiveness of interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 5b) What are the views and experiences of older people with learning disabilities and their carers about interventions or approaches to improve access and referral to health, social care and housing support services? 5c) What are the views and experiences of health, social care and other practitioners about interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 9a) What are the views and experiences of older people with learning disabilities and their carers about care and support in health settings? 9b) What are the views and experiences of health, social care and other practitioners about the care and support of older people with learning disabilities in health settings?
Quality of evidence	Recommendations 1.5.1, 1.5.5 and 1.5.3 are based on evidence from review question 9 about experiences in health settings for older people with learning disabilities. Overall, for question 9, 6 studies were located and they were moderate to good in terms of internal validity. Practitioner, service user and family views were all represented, providing useful insight into the experiences and preferences of older people with learning disabilities in relation to health assessments and interaction with practitioners although there were clear gaps in evidence about the perspective of health practitioners e.g. hospital practitioners or GPs. Recommendations 1.5.2 and 1.5.5 are based on evidence reviewed for question 5 about access and referral to health, social care and housing services. The evidence located for review question 5 (n=7) was moderate to good in terms of internal validity and provided data on the views and experiences of older people with learning disabilities, their families and carers and also of practitioners. There was no effectiveness evidence and the views and experiences data focussed on barriers to access rather than means of improving access and referral. Recommendation 1.5.6 is based on evidence reviewed for question 4 about information, training and advice for families, carers and advocates of older people with learning disabilities. Four papers were reviewed for question 4 and they provided data about the views and experiences of older people with learning disabilities and their families although no data on practitioner views. Overall, the internal validity of the studies was judged to be moderate. The studies focused on gaps in information, training and support needs for carers of older people. There was a lack of evidence trialling approaches or interventions, and gaps in evidence about training programmes for older people with

	learning disabilities, in terms of how best to provide them and how effective they are.
Economic considerations	No economic evidence was identified. Additional economic analysis was carried for this guideline to examine the cost-effectiveness of annual health checks. The findings of the analysis did not suggest that annual health checks were cost-effective - this was because insufficient evidence was available to confirm improvements in health-related quality and length of life to such an extent that they would justify the additional costs. The work was explorative and highlighted knowledge gaps in evidence on follow-on treatment and care for this population. The guideline committee thought that early recognition of health problems was a key priority in order to extend peoples' quantity of life and increase their quality of life but that this also needed to lead to the appropriate treatment and care. They emphasised that there was robust evidence that late recognition let to earlier, preventable death in this population. The guideline committee was particularly concerned about the large health inequalities experienced by this population. They agreed that in the current health system people experienced discrimination and that there was an urgent need for ensuring that better identification of health problems also led to the treatment and care that people needed in order to experience the same health-related quality of life as other older people with the same health conditions. Training for persons and their carers could help to ensure that health conditions were not missed and identified earlier. Whilst most of the economic considerations concerned outcomes, the guideline committee thought that there were also some potential cost savings linked to an earlier identification. They thought that this this prevented unnecessary medical appointments, which were otherwise often repeated without identifying the underlying health problem.
Evidence statements – numbered evidence statements from which the recommendations were developed	HS3: There is a small amount of evidence that breast screening is a frightening experience for women with learning disabilities. The quality of the evidence is moderate to good. A good quality study by Truesdale-Kennedy et al. (2011 ++) found that women with learning disabilities were stressed and anxious before and during a breast screen and afterwards felt relieved (p6). A moderate quality study (Lalor and Redmond 2009 +) found that older women with learning disabilities did not complete their examinations due to fear of the equipment and of staff, resulting in agitation and behaviour that challenges (p4). (Recommendations 1.5.1, 1.5.4 and 1.5.3) HS5: There is a small amount of evidence that family carers or advocates of older people with learning disabilities should be present during a hospital stay or medical appointment. The evidence is mainly good quality. A study by Webber et al (2010 ++) found that being present during hospital treatment meant carers could explain the person's needs, preferences and modes of communication. They could also assist with treatment, help reduce behaviour that challenges and in some cases, advocate to prevent premature transfer from hospital (p8). A study by Truesdale-Kennedy et al. (2011 ++) reported that women with learning disabilities felt breast screening would be less frightening

	if family members could accompany them (p6). (Recommendation 1.5.1) AR4: There is some evidence that a lack of awareness and understanding among practitioners about supporting older people with learning disabilities has the effect of reducing access to support. The quality of the evidence is good. Research in rural Australia (Wark et al. 2015 ++) showed that having a GP who knows the older person with a learning disability, understands their needs and can communicate well was a key aspect of providing access to health care and ensuring a ‘good life’ (p5). A Northern Ireland study (McIlfatrick et al. 2011 ++) found that health professionals have an important role in explaining breast examinations to women with learning disabilities and that this promotes access by putting them at ease and encourages them to attend appointments (p15). Similarly in a US study (Swaine et al 2013 ++) family carers believed that having a doctor who is competent with facilitating learning disabilities and explains a medical procedure in advance helped women with learning disabilities to access breast exams (p3). (Recommendation 1.5.2) AR5: There is a moderate amount of evidence that family carers have an important influence over whether older people with learning disabilities access support. The quality of the evidence is moderate to good. In the study by Dodd et al (2009 +) key workers said that one of the reasons older people with learning disabilities do not access specialist services is that families opt to support the person themselves and feel that formal services are therefore not necessary (p12). A US study by Coyle et al. (2016 +) reported that it can sometimes be problematic if families telephone the resource centre seeking financial or benefits advice for the person with learning disabilities unless they are established as the legal representative (p9). Practitioners in the McIlfatrick et al. study (2011 ++) said that carers can be helpful in supporting women with learning disabilities to access breast cancer screening. On the other hand they can act as a barrier to access if they do not believe screening to be something the person needs or if they think it will cause too much distress (p15). Finally, in the study by Swaine at al. (2013 ++) carers said the reason the older person with learning disabilities had accessed good quality health care was that they had themselves acted as the person’s champion (p3). (Recommendation 1.5.5) FCA5: There is a small amount of evidence that some family carers of older people with learning disabilities need specialist training, particularly in relation to additional conditions. The quality of the evidence is moderate. The study by Atkins and Loverseed (2012 +) found that carers wanted professional advice about how to communicate with the older person with a learning disability and this was particularly following a dementia diagnosis (p1). The study by Janicki et al. (2010 +) also found that family carers wanted training on specialist dementia care to help them provide the right support (p4). (Recommendation 1.5.6)
Other considerations	Recommendation 1.5.1 is based on HS3 which reports evidence about the anxiety experienced by older women with learning disabilities when they attended breast screening. It is also supported by H5 which reports that family members or carers

	should be present during medical appointments. The guideline committee agreed that on the basis of both evidence statements, older people with learning disabilities should be encouraged to have a family member present and this should not be limited to breast screening but ought to apply to all medical appointments and screening. The experts by experience strongly supported this and felt that it is necessary in hospital and GPs alike, which is why the recommendation is aimed at health practitioners in general. Recommendation 1.5.2 is based on evidence in AR4 that when health practitioners do not understand the older person, particularly in terms of their communication preferences, this can prevent access to medical examinations or treatment. The committee therefore agreed a recommendation that health practitioners should provide clear explanations about examinations. Simply providing what the practitioner perceives to be a clear explanation however is insufficient and in light of the Mental Capacity Act the committee agreed that all reasonable steps must be taken to ensure the person has understood the explanation. Recommendation 1.5.4 is based on HS3 about the anxiety experienced by women with learning disabilities before and during breast screening. The committee discussed the evidence and the experts by experience in particular provided ideas about how this anxiety could be addressed and how the experience of breast screening could be made less stressful. One of the ways of doing this would be to conduct the examination in a setting which is comfortable and familiar to the older person. Although the guideline committee acknowledged that it may not always be practical to give people this kind of choice, they agreed it should happen wherever possible. Recommendation 1.53 is also based on HS3 about the anxiety experienced by older women with learning disabilities before and during breast screening. It was developed on the basis of discussion among the committee about how anxieties relating to health appointments could be addressed. As well as the clear explanations recommended in 1.5.2 the committee felt it was important to emphasise that explanations should continue throughout (and not just leading up to) the examination and that if the person agrees, then their family and carers should also have the procedure explained so that they can provide additional support. Recommendation 1.5.5 is based on AR5 which highlights the important role that families play in helping older people with learning disabilities to access health appointments, including screening. Given that older people with learning disabilities face such difficulties in accessing health services the committee agreed 1.5.5 to ensure families are supported in their crucial role. Recommendation 1.5.6 is based on FCA5 which reports that families of older people with learning disabilities feel they have unmet training needs. The research specifically focussed on training to support people living with dementia but the guideline committee had a lengthy discussion and agreed that families

	would benefit from training in a much wider range of health issues. Given that the need for training in those other areas of health was extrapolated from evidence about the need for training in dementia care, the committee agreed to make it a 'consider', reflecting weaker evidence. In addition because the evidence base for training needs among families is weak (just 2 studies informed 1.5.6) the guideline committee also agreed that a recommendation for research on this subject should be made in order for findings to support stronger practice recommendations in future.

Topic/section heading	**Co-ordinating care and sharing information**
Recommendations	1.5.7 Managers in healthcare settings should identify a single lead practitioner to be the point of contact for older people with learning disabilities and their family members and carers. This practitioner could be a member of the community learning disability team or a nurse with experience in learning disabilities. 1.5.8 Ensure that everyone involved in the person's care and support shares information and communicates regularly about the person's health and any treatment they are having, for example by holding regular multidisciplinary meetings. Involve the person in all discussions. 1.5.9 Primary and secondary healthcare teams should identify at least 1 member of staff who develops specific knowledge and skills in working with older people with learning disabilities and acts as a champion, modelling and sharing good practice. Use the expertise of older people with learning disabilities to ensure the champion understands their needs. 1.5.10 Record a person's learning disability in their health records. With the person's consent, make sure all healthcare practitioners in community and acute settings can access this. Also record any specific needs or wishes, for example to do with the person's communication or mobility.
Research recommendations	The Guideline Committee agreed the following research recommendations to address gaps in evidence about training in self-management and the identification of health conditions: Research recommendation 2 a) What is the effectiveness and cost effectiveness of different ways of identifying age-related and other physical and mental health conditions, in older people with learning disabilities? b) What can mainstream and specialist health services do to facilitate: - early identification of health conditions in older people with learning disabilities? - equal access to health services in older people with learning disabilities? Research recommendation 3 What is the effectiveness and cost effectiveness of education programmes to improve information and advice and to support

	self-management of chronic health conditions (for example obesity, diabetes and cardiovascular disease) for older people with learning disabilities and their family members and carers?
Review questions	3a) What is the acceptability, effectiveness and cost effectiveness of providing information, advice and training to older people with learning disabilities? 3b) What are the views and experiences of older people with learning disabilities and their carers about information, advice and training to older people with learning disabilities? 3c) What are the views and experiences of health, social care and other practitioners about information, advice and training to older people with learning disabilities? 5a) What is the acceptability, effectiveness and cost effectiveness of interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 5b) What are the views and experiences of older people with learning disabilities and their carers about interventions or approaches to improve access and referral to health, social care and housing support services? 5c) What are the views and experiences of health, social care and other practitioners about interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 9a) What are the views and experiences of older people with learning disabilities and their carers about care and support in health settings? 9b) What are the views and experiences of health, social care and other practitioners about the care and support of older people with learning disabilities in health settings?
Quality of evidence	Recommendation 1.5.7 and 1.5.9 are based on evidence from review question 9 about experiences in health settings for older people with learning disabilities. Overall, for question 9, 6 studies were located and they were moderate to good in terms of internal validity. Practitioner, service user and family views were all represented, providing useful insight into the experiences and preferences of older people with learning disabilities in relation to health assessments and interaction with practitioners although there were clear gaps in evidence about the perspective of health practitioners e.g. hospital practitioners or GPs. Recommendation 1.5.8 is based on evidence reviewed for question 3 about information, training and advice for older people with learning disabilities. A total of 6 papers were included for this question and overall, their internal validity was good to moderate. Only one effectiveness study was found, although the results were of limited use due to methods issues. The views and experiences or older people with learning disabilities and their families were well represented in the evidence but only one study provided the practitioner perspective. The views studies provided important information about what works and what does not in providing information. There was a particular lack of evidence trialling approaches or interventions, and a gap in evidence about

	training for older people with learning disabilities, whether it is needed and how best to provide it. Recommendation 1.5.10 is based on evidence reviewed for question 5 about access and referral to health, social care and housing services. The evidence located for review question 5 (n=7) was moderate to good in terms of internal validity and provided data on the views and experiences of older people with learning disabilities, their families and carers and also of practitioners. There was no effectiveness evidence and the views and experiences data focussed on barriers to access rather than means of improving access and referral.
Economic considerations	No economic evidence was identified. The guideline committee agreed that having a lead practitioner was important to avoid poor co-ordination, which was often linked to additional costs because appointments and discussions among professionals needed to be repeated unnecessarily and more costly specialist services were used unnecessarily in place of non-specialised health and social care services. The guideline committee thought that Champions-in addition to carers - had an important role in ensuring that the person was able to keep appointments and this thus reduced the number of missed appointments, which was - together with unnecessary frequent or lengthy appointments - seen as a substantial cost factor. Champions also played a role in signposting to additional emotional, practical and social support utilising existing infrastructures, thus preventing the inappropriate of health and social care services.
Evidence statements – numbered evidence statements from which the recommendations were developed	HS3: There is a small amount of evidence that breast screening is a frightening experience for women with learning disabilities. The quality of the evidence is moderate to good. A good quality study by Truesdale-Kennedy et al. (2011 ++) found that women with learning disabilities were stressed and anxious before and during a breast screen and afterwards felt relieved (p6). A moderate quality study (Lalor and Redmond 2009 +) found that older women with learning disabilities did not complete their examinations due to fear of the equipment and of staff, resulting in agitation and behaviour that challenges (p4). (Recommendation 1.5.7) IAT3: There is a small amount of evidence that family and carers play a central role in supporting and advising older people with learning disabilities about their health conditions. The quality of the evidence is good. The study by Cardol et al (2012 ++) found that it is very important for older people with learning disabilities to have a trusted adult with them during medical check-ups. The role of the trusted adult includes asking questions to doctors and afterwards, explaining the answers in a way the person can understand (p3). The study by Young (2012 ++) confirmed that families and carers play the biggest part in supporting older people with learning disabilities to manage their heart condition. It is important to note that family support and support from staff needs to be well coordinated so that the actions of one do not undermine plans made by the other. The example of healthy eating is given in the study (p6). (Recommendation 1.5.8)

	HS2: There is a small amount of evidence that health practitioners lack understanding about the needs of older people with learning disabilities. A good quality study by Webber (2010 ++) found, that in the experience of carers, hospital practitioners seemed uncomfortable and inexperienced with older people with learning disabilities. This resulted in unmet personal care needs and poor communication. It also led to a lack of sensitivity about the importance of following people's personal routines and pain management plans. This lead to disruptive behaviour. In the worst cases, carers felt that this lack of understanding resulted in premature transfer from hospital and pressure on group homes to accept the resident following discharge (p8). Northway et al. (2016 +) found that when health practitioners respected the special insight that managers of supported living schemes have into residents' changing health needs, this provides a basis for effective joint working to address those needs. (Recommendation 1.5.9) AR4: There is a moderate amount of evidence that despite reported anxiety about the future, families of adults with learning disabilities do not carry out future planning. The quality of the evidence is mixed. The majority of participants in Dillenberger and McKerr (2011 +) had not discussed future provision of care and support with social services and avoided discussion within their families at the risk of causing distress. Similarly only a minority of parents in another study (Towers 2013 −) had spoken to practitioners about future planning. Families with relatives in group homes had clearly not considered future planning (Bigby et al. 2011 ++) and in Innes et al. (2012 −) families and supporters were unwilling or unable to undertake forward planning. (Recommendation 1.5.10)
Other considerations	Recommendation 1.5.7 is based on HS3 about the fear and anxiety surrounding breast examinations for older women with learning disabilities. The committee discussed different ways of eliminating this distress and agreed that one important means would be for the older person and their families to have a single point of contact in the context of health care. This lead practitioner would have experience in learning disabilities and would be accessible to the person and their family as a means of providing accessible information and support in health settings. Recommendation 1.5.8 is based on IAT3 about the important role that families and carers play in supporting and advising older people with learning disabilities in relation to health conditions. In this context the committee therefore agreed a recommendation to ensure that everyone involved in supporting the older person should share information and talk about the person's health and treatment plan. This includes families as well as relevant practitioners and on forum for this information sharing is multi-disciplinary meetings. Finally, the committee was also keen to emphasise that the individual should also be included in these discussions and that the recommendation should not be restricted to health but more generally to 'care and support'. Recommendation 1.5.9 is based on HS2 which reports evidence that health practitioners lack experience about the needs of older people with learning disabilities, resulting in unmet care needs

	and poor communication. The guideline committee recognised the problems described in the research and discussed at length how they could be addressed in practice. They agree that a member of staff within all primary and secondary healthcare teams should be appointed to act as a learning disabilities champion, modelling good practice and sharing their knowledge with other practitioners. This individual would therefore be distinct from the single point of contact recommended in 1.5.7. During discussions around the learning disabilities champion, the experts by experience felt strongly that the champion should develop their own expertise by learning from people with learning disabilities themselves. Finally, the committee discussed the potential resource implications of making this recommendation and their conclusions are reported above in 'economic considerations'. Recommendation 1.5.10 is based on AR4 which emphasises the importance of health practitioners having a good understanding of people with learning disabilities so that they can communicate effectively and promote access to care. In discussing this evidence the committee agreed about the importance of GPs building up their knowledge of the person and understanding their learning disability. The committee agreed that one means of achieving this would be to record details of the person's learning disability on their health records to give all health practitioners this understanding when they treat the person. The committee felt it would be important for practitioners to have ready access to the person's communication and mobility needs but these are only intended as examples.

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Topic/section heading	**Health checks and screening**
Recommendations	1.5.11 Offer older people with learning disabilities the same routine screening and health checks as other older people. 1.5.12 Recognise that older people with learning disabilities may need additional health surveillance to help them identify and communicate symptoms of age-related conditions. This could include providing information about annual health checks including what they involve and how to arrange them. 1.4.13 Discuss with people changes that may occur with age. Ask them about and monitor them for symptoms of common age-related conditions, including:

	- hearing loss and sight problems - blood pressure and cholesterol - prostate cancer - epilepsy - diabetes - osteoporosis - thyroid problems - menopausal symptoms. - mental health, including depression and dementia (also see recommendations 1.5.36 and 1.5.37).
Research recommendations	The Guideline Committee agreed the following research recommendation to address gaps in evidence about the identification of health conditions: Research recommendation 2 a) What is the effectiveness and cost effectiveness of different ways of identifying age-related and other physical and mental health conditions, in older people with learning disabilities? b) What can mainstream and specialist health services do to facilitate: - early identification of health conditions in older people with learning disabilities? - equal access to health services in older people with learning disabilities?
Review questions	1. What are the views and experiences of older people with learning disabilities and their carers about how care and support needs are identified, assessed and reviewed? 2. What are the views and experiences of health, social care and other practitioners about how the health and social care needs of older people with learning disabilities and their carers are identified, assessed and reviewed? 4a) What is the acceptability, effectiveness and cost effectiveness of providing information, advice, training and support for families, carers and advocates of older people with learning disabilities? 4b) What are the views and experiences of older people with learning disabilities and their carers about information, advice, training and support provided to families, carers and advocates? 4c) What are the views and experiences of health, social care and other practitioners about information, advice, training and support for families, carers and advocates? 9a) What are the views and experiences of older people with learning disabilities and their carers about care and support in health settings? 9b) What are the views and experiences of health, social care and other practitioners about the care and support of older people with learning disabilities in health settings?
Quality of evidence	Recommendation 1.5.11 is based on evidence reviewed for questions 1 and 2 about the identification, assessment and review of care and support needs among older people with learning disabilities. For question 1, there were 7 studies, which on

	average were moderate in terms of their internal validity. Only 1 study of moderate quality specifically answered question 2 and a further 4 studies provided data to answer both questions 1 and 2 because they reported practitioner views as well as views of older people with learning disabilities and their carers or families. There were gaps in the evidence about assessment and review of needs, with most of the data covering future planning. The gaps in the data led to discussions based on committee expertise, with crucial input from the experts by experience, including carers. Recommendation 1.5.12 is based on evidence from review question 9 about experiences in health settings for older people with learning disabilities. Overall, for question 9, 6 studies were located and they were moderate to good in terms of internal validity. Practitioner, service user and family views were all represented, providing useful insight into the experiences and preferences of older people with learning disabilities in relation to health assessments and interaction with practitioners although there were clear gaps in evidence about the perspective of health practitioners e.g. hospital practitioners or GPs. Recommendation 1.5.13 is partly based on evidence from review question 9, the quality of which is described above. It is also supported by evidence from review question 4 about information, training and advice for families, carers and advocates of older people with learning disabilities. Four papers were reviewed for question 4 and they provided data about the views and experiences of older people with learning disabilities and their families although no data on practitioner views. Overall, the internal validity of the studies was judged to be moderate. The studies focused on gaps in information, training and support needs for carers of older people. There was a lack of evidence trialling approaches or interventions, and gaps in evidence about training programmes for older people with learning disabilities, in terms of how best to provide them and how effective they are.
Economic considerations	Economic work was carried out on annual health checks. The work was exploratory due to the large gaps in evidence. The main findings were that: • additional resources might be needed to ensure that annual health checks can be provided cost-effectively; • more information is needed to understand how ageing-related health conditions are being identified and treated in this population; often there is not much knowledge about what would be cost-effective treatments making collaborative working between professionals and with the person and their carer particularly important; • annual health checks on their own might not always the most appropriate and cost-effective way of improving access to health care and reducing inequities. However, the committee noted that, despite the lack of evidence regarding cost-effectiveness of health checks, these are currently offered within the NHS. The committee therefore recommended that people should be given information about them and how to access them.

Evidence statements – numbered evidence statements from which the recommendations were developed	IAR2: There is a moderate amount of evidence that families and practitioners fail to identify the needs of older people with learning disabilities because they wrongly attribute behaviours and symptoms. The quality of this evidence is moderate. A study by Bowers et al (2014 +) found that in a group home, delays in seeking care happened because symptoms were wrongly attributed to ageing, dementia or other existing conditions, without alternatives being explored. Another moderate (+) quality study found that services and families attributed behaviour changes in adults with a learning disability to Down syndrome rather than considering the onset of dementia (Carling-Jenkins et al, 2015). A low quality systematic review (Innes et al 2012 −) found that in generic ageing services changes experienced due to ageing were attributed to a person's learning disability. Needs were therefore not identified. Finally, a UK study of paid care workers (Willis et al 2010 +) found they had difficulty separating signs and symptoms of the menopause from behaviours resulting from other causes. (Recommendation 1.5.11) HS4: There is a small amount of evidence that people's experiences of health check-ups or assessments are markedly improved when they are given clear explanations about what to expect. The quality of the evidence is good. A study by Truesdale-Kennedy et al. (2011 ++) reported that women with learning disabilities felt that breast screening would be far less frightening if they were provided with accessible information and given clear explanations about what to expect before the examination (p6). A study by Webber (2010 ++) found that carers were concerned about the failure of hospital practitioners to describe treatment and diagnosis to older people with learning disabilities on the assumption that they would not understand (p8). (Recommendation 1.5.12) HS2: There is a small amount of evidence that health practitioners lack understanding about the needs of older people with learning disabilities. A good quality study by Webber (2010 ++) found, that in the experience of carers, hospital practitioners seemed uncomfortable and inexperienced with older people with learning disabilities. This resulted in unmet personal care needs and poor communication. It also led to a lack of sensitivity about the importance of following people's personal routines and pain management plans. This lead to disruptive behaviour. In the worst cases, carers felt that this lack of understanding resulted in premature transfer from hospital and pressure on group homes to accept the resident following discharge (p8). Northway et al. (2016 +) found that when health practitioners respected the special insight that managers of supported living schemes have into residents' changing health needs, this provides a basis for effective joint working to address those needs. (Recommendation 1.5.13) There is a small amount of evidence that some family carers of older people with learning disabilities need specialist training, particularly in relation to additional conditions. The quality of the evidence is moderate. The study by Atkins and Loverseed (2012 +) found that carers wanted professional advice about how to communicate with the older person with a learning disability and

	this was particularly following a dementia diagnosis (p1). The study by Janicki et al. (2010 +) also found that family carers wanted training on specialist dementia care to help them provide the right support (p4). (1.5.13)
Other considerations	Recommendation 1.5.11 is based on IAR2 which reports evidence that families and practitioners fail to identify the needs of older people with learning because they wrongly attribute symptoms. The guideline committee recognised this as a significant problem, which some of them identified as 'diagnostic overshadowing'. The committee agreed that diagnostic overshadowing can be compounded by the difficulties that older people with learning disabilities often have in being able to identify and describe their own symptoms. They therefore agreed recommendation 1.5.11 to ensure health needs are identified through offering older people with learning disabilities the same routine screening as other older people while also recognising that this population may need additional oversight from health practitioners to help them identify their own symptoms. Recommendation 1.5.12 is based on HS4 which reports evidence that the health needs of older people with learning disabilities should be identified through tests and checks about which clear explanations are consistently provided. Although annual health checks exist they are conducted inconsistently among the older learning disabled population with some being carried out over the telephone. The committee therefore reached consensus about the need for a recommendation to give people information about annual health checks. They felt this would help to address access problems in relation to health advice and monitoring. Recommendation 1.5.13 is based on HS2 reporting evidence about health practitioners lacking understanding about older people with learning disabilities. The committee agreed that this has negative impacts including unmet health needs. They concluded that the recommendation was therefore needed to encourage practitioners to talk to people with learning disabilities about symptoms they may experience in old age and also to help them recognise those symptoms for themselves. The list of age related conditions provided as examples in the recommendation are derived from FCA5, which highlights the prevalence of dementia among adults with learning disabilities. The group then reached consensus about other important conditions and symptoms with which people with learning disabilities should be familiar.

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Topic/section heading	**Health checks and screening (continued)**
Recommendations	1.5.14 If the person is having an annual health check, give them information about other available services, including a care and support assessment under the Care Act 2014 if they have not already had one. 1.5.15 If the person is having an annual health check, ask if they are registered with a dentist, how often they see the dentist and

	check that they understand the importance of looking after their teeth and mouth. 1.5.16 Give people clear, accessible and practical information and advice about keeping well as they grow older. Tell them about, and help them to access, preventative services such as breast screening, smear tests, testicular and prostate checks and dental checks. 1.5.17 When designing and delivering breast screening services, address specific barriers to accessing breast screening among older women with learning disabilities, including support to: • understand breast cancer • understand the screening procedure • perform breast self-examination • understand any information provided • attend appointments.
Research recommendations	The Guideline Committee agreed the following research recommendations to address gaps in evidence about the identification of health conditions and training in self-management: Research recommendation 2 a) What is the effectiveness and cost effectiveness of different ways of identifying age-related and other physical and mental health conditions, in older people with learning disabilities? b) What can mainstream and specialist health services do to facilitate: - early identification of health conditions in older people with learning disabilities? - equal access to health services in older people with learning disabilities? Research recommendation 3 What is the effectiveness and cost effectiveness of education programmes to improve information and advice and to support self-management of chronic health conditions (for example obesity, diabetes and cardiovascular disease) for older people with learning disabilities and their family members and carers?
Review questions	3a) What is the acceptability, effectiveness and cost effectiveness of providing information, advice and training to older people with learning disabilities? 3b) What are the views and experiences of older people with learning disabilities and their carers about information, advice and training to older people with learning disabilities? 3c) What are the views and experiences of health, social care and other practitioners about information, advice and training to older people with learning disabilities? 5a) What is the acceptability, effectiveness and cost effectiveness of interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities?

	5b) What are the views and experiences of older people with learning disabilities and their carers about interventions or approaches to improve access and referral to health, social care and housing support services? 5c) What are the views and experiences of health, social care and other practitioners about interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 9a) What are the views and experiences of older people with learning disabilities and their carers about care and support in health settings? 9b) What are the views and experiences of health, social care and other practitioners about the care and support of older people with learning disabilities in health settings?
Quality of evidence	Recommendation 1.5.14 is based on evidence reviewed for review question 9 about experiences in health settings for older people with learning disabilities. Overall, for question 9, 6 studies were located and they were moderate to good in terms of internal validity. Practitioner, service user and family views were all represented, providing useful insight into the experiences and preferences of older people with learning disabilities in relation to health assessments and interaction with practitioners although there were clear gaps in evidence about the perspective of health practitioners e.g. hospital practitioners or GPs. Recommendation 1.5.15 is based on evidence reviewed for question 5 about access and referral to health, social care and housing services. The evidence located for review question 5 (n=7) was moderate to good in terms of internal validity and provided data on the views and experiences of older people with learning disabilities, their families and carers and also of practitioners. There was no effectiveness or cost effectiveness evidence and the views and experiences data focussed on barriers to access rather than means of improving access and referral. Recommendation 1.5.16 is based on evidence from review question 3 about information, training and advice for older people with learning disabilities. A total of 6 papers were included for this question and overall, their internal validity was good to moderate. Only one effectiveness study was found, although the results were of limited use due to methods issues. The views and experiences or older people with learning disabilities and their families were well represented in the evidence but only one study provided the practitioner perspective. The views studies provided important information about what works and what does not in providing information. There was a particular lack of evidence trialling approaches or interventions, and a gap in evidence about training for older people with learning disabilities, whether it is needed and how best to provide it. Recommendation 1.5.16 is also supported by evidence reviewed for question 5, the quality of which is described above. Recommendation 1.5.17 is also based on evidence reviewed for question, the quality of which is described above.

Economic considerations	No economic evidence was identified. The additional economic analysis on annual health checks covered aspects of early identification and highlighted the importance and need for more evidence in this area. In addition, the guideline committee discussed the importance of personalised information and advice. They thought that information and advice that was not provided in a personalised way, was wasteful as it would not lead to changes in health outcomes. They also discussed the devastating impact on the person if dental care needs were not met (which they reported was common in current practice), which could lead to more severe health problems, which would then require more expensive treatment and care.
Evidence statements – numbered evidence statements from which the recommendations were developed	HS4: There is a small amount of evidence that people's experiences of health check-ups or assessments are markedly improved when they are given clear explanations about what to expect. The quality of the evidence is good. A study by Truesdale-Kennedy et al. (2011 ++) reported that women with learning disabilities felt that breast screening would be far less frightening if they were provided with accessible information and given clear explanations about what to expect before the examination (p6). A study by Webber (2010 ++) found that carers were concerned about the failure of hospital practitioners to describe treatment and diagnosis to older people with learning disabilities on the assumption that they would not understand (p8). (Recommendation 1.5.14) AR1: There is a small amount of evidence that older people with learning disabilities who live independently have poor access to dental care. The quality of the evidence is moderate. Mac Giolla Phadraig et al. (2014 +) found that the proportion of regular dentist attenders was lowest among people living independently and this is perhaps owing to the fact that dentists generally visit selected residential services on an annual basis (p1). (Recommendation 1.5.15) IAT1: There is a moderate amount of evidence that advice about health experiences is not always presented clearly enough for older people with learning disabilities. This leads to confusion and a lack of understanding. The quality of this evidence is moderate to good. A study from the Netherlands (Cardol et al. 2012 ++) found that not one of the participants had received written information about their health condition (diabetes) in a way they could understand (p3). A UK study by Willis (2008 +) also found that 12 out 18 respondents had received no information about the menopause and for 3 women, the television had been their source of information. Any information that had been provided was produced in an inappropriate format (p4). Another UK study by Young et al. (2012) emphasized that information for older people with learning disabilities needs to be presented in a meaningful way so they can manage their heart condition (p6). Finally, Willis et al. 2010 (+) found that care workers wanted specific training to help them communicate with older women with learning disabilities and provide them with advice and support through the menopause (p8). (Recommendation 1.5.16) AR2: There is some evidence that older people with learning disabilities can lack understanding and awareness about the

	importance of health interventions and this can limit their access to services. The quality of this evidence is mainly moderate. Mac Giolla Phadraig et al. (2014 +) found that irregular dentist attenders made a choice not to access this service – sometimes out of fear – or because they were unaware of the importance of dental checks (p1). Dodd et al. (2009 +) found that one of the reasons older adults were not accessing specialist learning disability services was that individuals themselves did not want this support (p12). McIlfatrick et al (2011 ++) identified a lack of understanding about breast examinations and breast cancer among women with learning disabilities, which acted as a barrier to accessing breast screening services (p15). (Recommendation 1.5.16) IAT3: There is a moderate amount of evidence that older people with learning disabilities have limited access to support because of a lack of services designed specifically to address their needs and preferences. The quality of the evidence is mostly moderate. Wark et al. (2015 ++) found that in rural Australia, older people with learning disabilities had to travel very long distances from home in order to access specialist health services. In addition, where learning disability services were available locally, access was limited by having few, if any, options (p5). Benbow et al. (2011 +) reported that learning disability practitioners said psychiatry services for older people in the UK specifically exclude people with learning disabilities (p8). The US study by Coyle (2016 +) reported clear difficulties from a practitioner perspective around being able to provide resources and support to older people with learning disabilities. As a result staff admitted to not addressing the needs of the specific population in the provision of services although it was something they recognized they ought to in future (p9). Finally, a study conducted in Ireland (Dodd et al. 2009 +) found that one of the reasons older adults with learning disabilities did not access specialist learning disability services was that families judged that they were not appropriate to meet the person's needs (p12). (Recommendation 1.5.16) AR6: There is a small amount of evidence that practical difficulties associated with health appointments can act as a barrier against older people with learning disabilities accessing support. The quality of the evidence is good. In McIlfatrick et al. (2011 ++) health practitioners said that women with learning disabilities could find it difficult to access breast cancer screening because they have difficulties dealing with correspondence and attending appointments. This underlines evidence already reviewed for questions 1 and 2 about difficulties in attending screening and assessments (p15). The US study by Swaine et al. (++) also chimed with this when family caregivers said that convenient appointments for them as carers helped in ensuring older people with learning disabilities could access breast cancer screening (p3). (Recommendations 1.5.16 and 1.5.17)
Other considerations	Recommendation 1.5.14 is based on HS4 which reports that older people with learning disabilities require clear information and explanations. The group agreed that during health checks, the older person should be given information about other available services including care and support assessments.

	Recommendation 1.5.15 is based on AR1 which reports evidence that older people with learning disabilities living independently have poor access to dental care. This resonated with the committee including the experts by experience although they all disagreed that the situation was much better in residential settings. They therefore agreed a recommendation that as part of health checks, people are asked about their dentist and their understanding about the importance of dental care is explored. Recommendation 1.5.16 is based on evidence from IAT3 that older people with learning disabilities are reliant on families and carers for access health service and information. The experts by experience felt that instead people should be empowered to make their own choices and informed decisions, which is why the recommendation is for people to be given the information and in an accessible format. This also helps to address the problems identified in AR2 that older people with learning disabilities lack understanding about the importance of health services and IAT2 which reports that older people with learning disabilities need to be better supported to manage their own conditions. Finally, this recommendation is also supported by AR6, which highlighted that there are practical difficulties which prevent older people with learning disabilities accessing appointments. The guideline committee therefore agreed that as well as being told about health services such as screening, older people should be helped to access them. Recommendation 1.5.17 is also based on AR6, in particular the study by McIlfratick et al. (2011 ++) which describes the practical barriers experienced by women trying to access breast screening. The study identified difficulties in handling correspondence and physically attending the appointment. Combined with the research findings and their own expertise, the committee developed a list of specific elements of support to promote breast screening awareness and enable attendance at appointments.

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Topic/section heading	**Primary care**
Recommendations	1.5.18 Design primary care and community services so that older people with learning disabilities can see the same GP and other healthcare practitioners, wherever possible, to help practitioners: • become familiar with the person's medical history, which the person may have difficulty remembering themselves • build good relationships and understand the person's usual behaviour and communication needs. 1.5.19 General practices should allocate a named member of staff to remind older people with learning disabilities about appointments for screening and health examinations. This staff member should help the person attend the appointment by:

	• using each person's preferred method of communication • giving them information in a way they can understand • ensuring the person understands the reason for the appointment and why it is important • finding out their transport needs • making reasonable adjustments to help the person and their carer or supporter to attend. 1.5.20 If the person is diagnosed with a health condition give them, and their family members and carers, accessible information on the following (taking time to explain it to them as well): • symptoms and management • benefits, and potential side effects, of treatment • how to take their prescribed medicines. 1.5.21 Support older people to manage their own health conditions by getting to know them and adapting health advice to suit their personal choices and the activities they already enjoy (for example, playing football).
Research recommendations	The Guideline Committee agreed the following research recommendations to address gaps in evidence about the identification of health conditions and training in self-management: Research recommendation 2 a) What is the effectiveness and cost effectiveness of different ways of identifying age-related and other physical and mental health conditions, in older people with learning disabilities? b) What can mainstream and specialist health services do to facilitate: - early identification of health conditions in older people with learning disabilities? - equal access to health services in older people with learning disabilities? Research recommendation 3 What is the effectiveness and cost effectiveness of education programmes to improve information and advice and to support self-management of chronic health conditions (for example obesity, diabetes and cardiovascular disease) for older people with learning disabilities and their family members and carers?
Review questions	3a) What is the acceptability, effectiveness and cost effectiveness of providing information, advice and training to older people with learning disabilities? 3b) What are the views and experiences of older people with learning disabilities and their carers about information, advice and training to older people with learning disabilities? 3c) What are the views and experiences of health, social care and other practitioners about information, advice and training to older people with learning disabilities?

	5a) What is the acceptability, effectiveness and cost effectiveness of interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 5b) What are the views and experiences of older people with learning disabilities and their carers about interventions or approaches to improve access and referral to health, social care and housing support services? 5c) What are the views and experiences of health, social care and other practitioners about interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities?
Quality of evidence	Recommendations 1.5.18 and 1.5.19 are both based on evidence from review question 5 about access and referral to health, social care and housing services. The evidence located for review question 5 (n=7) was moderate to good in terms of internal validity and provided data on the views and experiences of older people with learning disabilities, their families and carers and also of practitioners. There was no effectiveness evidence and the views and experiences data focussed on barriers to access rather than means of improving access and referral. Recommendation 1.5.20 and 1.5.21 are based on evidence reviewed for question 3 about information, training and advice for older people with learning disabilities. A total of 6 papers were included for this question and overall, their internal validity was good to moderate. Only one effectiveness study was found, although the results were of limited use due to methods issues. The views and experiences or older people with learning disabilities and their families were well represented in the evidence but only one study provided the practitioner perspective. The views studies provided important information about what works and what does not in providing information. There was a particular lack of evidence trialling approaches or interventions, and a gap in evidence about training for older people with learning disabilities, whether it is needed and how best to provide it.
Economic considerations	No economic evidence was identified. The guideline committee thought that the recommendations would importantly help to reduce missed and late diagnosis of health conditions, and thus improve person's quality of life and reduce premature death, as well as avoid the costs of missed appointments. In particular having an allocated member of staff at General Practice was thought to help achieve this. The guideline committee thought that a successful example was the dementia friendly practice.
Evidence statements – numbered evidence statements from which the recommendations were developed	AR4: There is some evidence that a lack of awareness and understanding among practitioners about supporting older people with learning disabilities has the effect of reducing access to support. The quality of the evidence is good. Research in rural Australia (Wark et al. 2015 ++) showed that having a GP who knows the older person with a learning disability, understands their needs and can communicate well was a key aspect of providing access to health care and ensuring a 'good life' (p5). A Northern Ireland study (McIlfatrick et al. 2011 ++) found that

	health professionals have an important role in explaining breast examinations to women with learning disabilities and that this promotes access by putting them at ease and encourages them to attend appointments (p15). Similarly in a US study (Swaine et al 2013 ++) family carers believed that having a doctor who is competent with facilitating learning disabilities and explains a medical procedure in advance helped women with learning disabilities to access breast exams (p3). (Recommendation1.5.18) AR2: There is some evidence that older people with learning disabilities can lack understanding and awareness about the importance of health interventions and this can limit their access to services. The quality of this evidence is mainly moderate. Mac Giolla Phadraig et al. (2014 +) found that irregular dentist attenders made a choice not to access this service – sometimes out of fear – or because they were unaware of the importance of dental checks (p1). Dodd et al. (2009 +) found that one of the reasons older adults were not accessing specialist learning disability services was that individuals themselves did not want this support (p12). McIlfatrick et al (2011 ++) identified a lack of understanding about breast examinations and breast cancer among women with learning disabilities, which acted as a barrier to accessing breast screening services (p15). (Recommendation 1.5.19) AR6: There is a small amount of evidence that practical difficulties associated with health appointments can act as a barrier against older people with learning disabilities accessing support. The quality of the evidence is good. In McIlfatrick et al. (2011 ++) health practitioners said that women with learning disabilities could find it difficult to access breast cancer screening because they have difficulties dealing with correspondence and attending appointments. This underlines evidence already reviewed for questions 1 and 2 about difficulties in attending screening and assessments (p15). The US study by Swaine et al. (++) also chimed with this when family caregivers said that convenient appointments for them as carers helped in ensuring older people with learning disabilities could access breast cancer screening (p3). (Recommendation 1.5.19) IAT1: There is a moderate amount of evidence that advice about health experiences is not always presented clearly enough for older people with learning disabilities. This leads to confusion and a lack of understanding. The quality of this evidence is moderate to good. A study from the Netherlands (Cardol et al. 2012 ++) found that not one of the participants had received written information about their health condition (diabetes) in a way they could understand (p3). A UK study by Willis (2008 +) also found that 12 out 18 respondents had received no information about the menopause and for 3 women, the television had been their source of information. Any information that had been provided was produced in an inappropriate format (p4). Another UK study by Young et al. (2012) emphasized that information for older people with learning disabilities needs to be presented in a meaningful way so they can manage their heart condition (p6). Finally, Willis et al. 2010 (+) found that care workers wanted

	specific training to help them communicate with older women with learning disabilities and provide them with advice and support through the menopause (p8). (Recommendation 1.5.20) IAT2: There is a moderate amount of evidence that older people with learning disabilities need to be better supported to manage their own health conditions. The quality of the evidence is mainly good. The study by Cardol et al. (2012 ++) found that older people with learning disabilities needed support to become more confident and have greater understanding so they could self-manage their diabetes (p3). The New Zealand study by Whitehead et al (2016 ++) showed that with support and through negotiation adults with mild to moderate learning disabilities can manage their own diabetes, even in difficult areas such as maintaining a healthy diet, which required encouragements and timely reminders from support staff. A UK study by Willis (2008 +) found that the older women in the study had no experience of involvement in managing the menopause and this may be due to the fact that they are used to being told what is best for them. They were reluctant to ask questions or discuss what was happening to them (p4). The study by Young (2012 ++) found that older people with learning disabilities needed more practical support to be able to manage their heart condition and that changes to their lifestyle would be far easier to achieve if they are actively involved in planning (p6). (Recommendation 1.5.21)
Other considerations	Recommendation 1.5.18 is based on AR4 which provides evidence that a lack of awareness and understanding among practitioners about supporting older people with learning disabilities has the effect of reducing access to support. The research findings resonated with the committee, especially the experts by experience. They therefore agreed recommendation 1.4.18 to emphasise the importance of practitioners establishing a relationship with older people with learning disabilities, which would help them to understand their needs, for example around communication. They agreed that one of the key ways of enabling this would be for the same GP to see the person, wherever possible. Recommendation 1.5.19 is based on evidence that older people with learning disabilities lack understanding about the importance of health interventions and this is something that restricts access to appropriate support or treatment. In discussing this evidence the committee debated how this could be addressed and the experts by experience had some clear views about what would improve their understanding and encourage them to attend health appointments and screening. They said they would like someone to make direct contact with them to ensure they do not miss appointments and that person could also usefully describe appointments such as screening and explain why they are important. The committee eventually concluded that general practices should allocate a named member of staff to perform this role and they agreed a number of examples of things the staff member could do to support attendance Recommendation 1.5.20 is based on IAT1 which reports evidence that advice and information about health is not always presented clearly enough for older people with learning disabilities to

	understand. The guideline committee agreed that this is a common problem and discussed ways of overcoming it. They felt it was the practitioners responsibility to provide accessible information about specific issues when they give a diagnosis to an older person with a learning disability. Where appropriate, the information should also be given to the person's family. In particular the committee felt that families or carers should have information about the management of medication, reasons for the dosage and advice about how the treatment is likely to affect the person. Recommendation 1.5.21 is based on evidence that older people with learning disabilities need more support to manage their own health conditions. The evidence suggested that people could be enabled to manage their conditions and live healthier lifestyles if advice about how to do so was tailored to their own preferences and interests and communicated in a way they understand. The evidence related to managing heart conditions and diabetes so the committee agreed to extrapolate the findings and make the recommendation apply to health conditions in general. The most important point they intended to communicate was that strategies to enable self-management should be individualised.

Topic/section heading	**Dental care**
Recommendations	1.5.22 Commissioners and managers should ensure support staff have knowledge of oral health so they can support older people with learning disabilities to maintain good oral health and access dental services. 1.5.23 Dental practices should ensure their services are accessible to older people with learning disabilities, for example by: • reminding people about their appointments by phone • sending letters in an accessible format, for example Easy Read • suggesting that the person brings a carer or supporter with them • ensuring staff have the skills to communicate with people with learning disabilities and put them at ease. 1.5.24 For further guidance on managing oral health see the NICE guidelines on: • oral health promotion: general dental practice • oral health for adults in care homes.
Research recommendations	The Guideline Committee agreed the following research recommendation to address gaps in evidence about the identification of health conditions: Research recommendation 2 a) What is the effectiveness and cost effectiveness of different ways of identifying age-related and other physical and mental health conditions, in older people with learning disabilities?

	b) What can mainstream and specialist health services do to facilitate: - early identification of health conditions in older people with learning disabilities? - equal access to health services in older people with learning disabilities?
Review questions	5a) What is the acceptability, effectiveness and cost effectiveness of interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 5b) What are the views and experiences of older people with learning disabilities and their carers about interventions or approaches to improve access and referral to health, social care and housing support services? 5c) What are the views and experiences of health, social care and other practitioners about interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities?
Quality of evidence	Recommendations 1.5.22 and 1.5.23 are based on evidence reviewed for question 5 about access and referral to health, social care and housing services. The evidence located for review question 5 (n=7) was moderate to good in terms of internal validity and provided data on the views and experiences of older people with learning disabilities, their families and carers and also of practitioners. There was no effectiveness evidence and the views and experiences data focussed on barriers to access rather than means of improving access and referral. Recommendation 1.5.22 is based on discussions about the evidence for review question 5, the quality of which is described above, and is designed to sign post across to other relevant NICE guidelines.
Economic considerations	No economic evidence was identified. The guideline committee discussed that the lack of access to dental care in the community could lead to the need for more complicated and costly dental procedures that require a dental hospital visit, which might in rare circumstances even lead to an admission. The guideline committee agreed that dental health was a priority area as many people currently suffered from bad dental health, which could lead to more severe problems including lack of food intake and gastrointestinal disorders.
Evidence statements – numbered evidence statements from which the recommendations were developed	AR1: There is a small amount of evidence that older people with learning disabilities who live independently have poor access to dental care. The quality of the evidence is moderate. Mac Giolla Phadraig et al. (2014 +) found that the proportion of regular dentist attenders was lowest among people living independently and this is perhaps owing to the fact that dentists generally visit selected residential services on an annual basis (p1). (Recommendations 1.5.22 and 1.5.23)
Other considerations	Recommendation 1.5.22 is based on evidence in AR1 that older people with learning disabilities living in the community have poor access to dental services. In discussing this evidence the committee actually felt that the problem applied to all older people

	with learning disabilities. For this reason they agreed the recommendation should refer to all support staff (whether in residential, group or family home settings) and their role in supporting people to have good oral health. They agreed it is the responsibility of commissioners and managers to ensure this happens. Recommendation 1.5.23 is also based on AR1 about poor access to dental care. In discussing the evidence, one of the experts by experience described how well their own dentist supports them to attend appointments. The committee reached consensus that these examples should be incorporated in 1.5.23 to provide guidance on how dental practices should be more accessible to older people with learning disabilities. Finally recommendation 1.5.24 was included as a signpost to other relevant NICE guidelines which provide advice about managing oral health.

Topic/section heading	**Outpatient appointments**
Recommendations	1.5.25 Hospitals should arrange for the person and a family member or carer to visit the hospital before their outpatient appointment to meet the staff who will conduct any tests or examinations, see the equipment that will be used and identify what adjustments will be needed. Before and during a hospital stay 1.5.26 When planning a hospital admission, arrange a pre-admission planning meeting, including the hospital liaison team or liaison nurse, a representative of the community learning disability team, the person and their family members and carers. At this meeting: • complete the pre-admission documentation, which should include information from the person's hospital passport • discuss any reasonable adjustments needed, for example, arranging for the person to visit the hospital before their admission to meet the learning disability liaison nurse who will be their contact. 1.5.27 Hospitals should actively encourage staff to use pre-admission documents and flagging systems so that all relevant hospital staff know about the person's learning disability. At discharge, review how well this is working. 1.5.28 Hospitals should develop policies and guidance to enable someone chosen by the person to stay with them throughout their inpatient stay. This should include providing facilities for them to stay overnight. 1.5.29 Hospital staff should continue to offer health and personal care (toileting, washing, nutrition and hydration) to older people

	with learning disabilities even if they have a family member or carer there to support them. 1.5.30 For further guidance on planning admission and admitting adults with identified social care needs to hospital, see NICE's guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	9a) What are the views and experiences of older people with learning disabilities and their carers about care and support in health settings? 9b) What are the views and experiences of health, social care and other practitioners about the care and support of older people with learning disabilities in health settings?
Quality of evidence	Recommendations 1.5.25, 1.5.26, 1.5.27, 1.5.28, 1.5.29 and 1.5.30 are all based on the evidence reviewed for question 9 about experiences in health settings for older people with learning disabilities. Overall, for question 9, 6 studies were located and they were moderate to good in terms of internal validity. Practitioner, service user and family views were all represented, providing useful insight into the experiences and preferences of older people with learning disabilities in relation to health assessments and interaction with practitioners although there were clear gaps in evidence about the perspective of health practitioners e.g. hospital practitioners or GPs.
Economic considerations	No economic evidence was identified. The guideline committee thought that providing adequate overnight possibilities for carers was often an important factor in ensuring the person was able to stay in hospital overnight as staff on their own were often not able not cope with the person during night. They thought that additional preparation time as well as support to the person and the carer was essential for a speedier treatment and quicker discharge. For example, if the additional support that the carer could provide helped people to recover quicker and better communication helped preventing a delay in discharge. The guideline committee also emphasised the importance that also personal assistants needed to be allowed to stay on wards overnight if necessary (for example if no carer was available); they thought that this did not always have an additional cost attached since they were support staff, who were already paid for (for example by personal budgets).
Evidence statements – numbered evidence statements from which the recommendations were developed	HS3: There is a small amount of evidence that breast screening is a frightening experience for women with learning disabilities. The quality of the evidence is moderate to good. A good quality study by Truesdale-Kennedy et al. (2011 ++) found that women with learning disabilities were stressed and anxious before and during a breast screen and afterwards felt relieved (p6). A moderate quality study (Lalor and Redmond 2009 +) found that older women with learning disabilities did not complete their examinations due to fear of the equipment and of staff, resulting in agitation and behaviour that challenges (p4). (Recommendation 1.5.25)

	HS5: There is a small amount of evidence that family carers or advocates of older people with learning disabilities should be present during a hospital stay or medical appointment. The evidence is mainly good quality. A study by Webber et al (2010 ++) found that being present during hospital treatment meant carers could explain the person's needs, preferences and modes of communication. They could also assist with treatment, help reduce behaviour that challenges and in some cases, advocate to prevent premature transfer from hospital (p8). A study by Truesdale-Kennedy et al. (2011 ++) reported that women with learning disabilities felt breast screening would be less frightening if family members could accompany them (p6). (Recommendations 1.5.26, 1.5.28 and 1.5.29) HS2: There is a small amount of evidence that health practitioners lack understanding about the needs of older people with learning disabilities. A good quality study by Webber (2010 ++) found, that in the experience of carers, hospital practitioners seemed uncomfortable and inexperienced with older people with learning disabilities. This resulted in unmet personal care needs and poor communication. It also led to a lack of sensitivity about the importance of following people's personal routines and pain management plans. This lead to disruptive behaviour. In the worst cases, carers felt that this lack of understanding resulted in premature transfer from hospital and pressure on group homes to accept the resident following discharge (p8). Northway et al. (2016 +) found that when health practitioners respected the special insight that managers of supported living schemes have into residents' changing health needs, this provides a basis for effective joint working to address those needs. (Recommendation 1.5.27)
Other considerations	Recommendation 1.5.25 is based on evidence in HS3 that attending breast screening is a frightening experience for older women with learning disabilities. In discussing the evidence the committee actually felt that it is similarly frightening for older people with learning disabilities to attend any kind of hospital appointment for tests and examinations. The experts by experience argued that an effective way of addressing this would be for the person and their carers to visit the hospital before the date of the test in order to meet the staff who will conduct the test and familiarise themselves with the environment. The committee agreed that it should be the responsibility of the hospital to arrange these visits. Recommendation 1.5.26 is based on evidence in HS5 about the importance of having families or carers present during appointments, for example to help with explanations about the person's needs, preferences and modes of communication including any reasonable adjustments that may be required. The committee agreed that in order to ensure this knowledge sharing and planning occurs from the beginning then families should be involved in pre admission planning meetings as should a representative from the community learning disability team as well as the person themselves Recommendation 1.5.27 is based on evidence in HS2 that practitioners lack understanding about the needs of older people

	with learning disabilities. It is also supported by evidence in HS4 that people's experiences of health check ups or examinations are markedly improved when they are given clear explanations. The committee agreed that in the hospital context where people are likely to come into contact with a range of practitioners then the person's learning disability should be flagged in pre admission documentation. Staff will then know about the learning disability and be prepared to communicate appropriately, ensuring the person has a clear explanation of any test or treatment. Recommendation 1.5.28 is based on HS5 about the importance of having families or carers present during appointments or a stay in hospital, for example to help with explanations about the person's needs or to provide care. The committee agreed about the importance of this and therefore developed 1.5.28 giving hospitals the responsibility to accommodate a family member or carer chosen by the older person. Recommendation 1.5.29 is also based on HS5 about the importance of having families or carers present during appointments or a stay in hospital. In discussing the evidence, with which the committee agreed, they were also cautious about hospital practitioners relying too heavily on family members who may be staying with the older person. Therefore in 1.5.29 they aimed to emphasise that hospital practitioners should continue to provide the health and personal care that they otherwise would if the family carer was not present. The committee felt this was a very important message, which is why it is a separate recommendation, rather than being an element of 1.5.28. Recommendation 1.5.30 was developed to sign post practitioners to the NICE guideline on transitions between hospital and home, the principles of which the committee agreed should also be followed for older people with learning disabilities.

Topic/section heading	**Transfer of care from hospital**
Recommendations	1.5.31 Invite family members, carers or advocates to pre-discharge meetings, as well as the person themselves. 1.5.32 If the discharge plan involves support from family members or carers, take into account their: • willingness and ability to provide support • circumstances, needs and aspirations • relationship with the person • need for respite. [This recommendation is adapted from the NICE guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.] 1.5.33 Give the person (and their family members and carers) an accessible copy of their discharge plan when they are discharged, and make sure their GP has a copy within 24 hours. Make sure everyone knows what will happen next in the person's care and support.

	[This recommendation is adapted from the NICE guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.] 1.5.34 After the person is discharged, the hospital learning disability liaison nurse, community learning disability teams and primary care practitioners should work together to provide ongoing support to the person to help them manage their health conditions. 1.5.35 For further guidance on discharging adults with identified social care needs from hospital, see NICE's guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	9a) What are the views and experiences of older people with learning disabilities and their carers about care and support in health settings? 9b) What are the views and experiences of health, social care and other practitioners about the care and support of older people with learning disabilities in health settings?
Quality of evidence	Recommendations 1.5.31, 1.5.32, 1.5.33, 1.5.34 and 1.5.35 are all based on evidence from review question 9 about experiences in health settings for older people with learning disabilities. Overall, for question 9, 6 studies were located and they were moderate to good in terms of internal validity. Practitioner, service user and family views were all represented, providing useful insight into the experiences and preferences of older people with learning disabilities in relation to health assessments and interaction with practitioners although there were clear gaps in evidence about the perspective of health practitioners e.g. hospital practitioners or GPs.
Economic considerations	No economic evidence was identified. The guideline committee thought that the recommendations above were likely to prevent a delay in discharge and hospital readmissions and achieve potentially important cost savings from a government perspective.
Evidence statements – numbered evidence statements from which the recommendations were developed	HS5: There is a small amount of evidence that family carers or advocates of older people with learning disabilities should be present during a hospital stay or medical appointment. The evidence is mainly good quality. A study by Webber et al (2010 ++) found that being present during hospital treatment meant carers could explain the person's needs, preferences and modes of communication. They could also assist with treatment, help reduce behaviour that challenges and in some cases, advocate to prevent premature transfer from hospital (p8). A study by Truesdale-Kennedy et al. (2011 ++) reported that women with learning disabilities felt breast screening would be less frightening if family members could accompany them (p6). (Recommendations 1.5.31, 1.5.32 and 1.5.33)
Other considerations	Recommendation 1.5.31 is based on HS5 about the importance of having families or carers present during appointments or a stay in hospital, for example to help with explanations about the

	person's needs. The committee agreed this is important and that therefore families, carers or advocates should be a part of pre discharge meetings – as well as the person themselves. Recommendation 1.5.32 is also based on HS5 about the important role of family and carers. Although the evidence highlights the role that families play in supporting older people with learning disabilities, the committee felt that this contribution should not be assumed. During discharge planning, their willingness and ability to provide support following discharge should be carefully and sensitively investigated. Due to the overlap with the NICE guideline on transitions between hospital and home the committee agreed to adapt a recommendation from that guideline, in order to avoid duplication. Recommendation 1.5.33 is also based on HS5 about the important role of family and carers and their potential contribution to facilitating transfers from hospital. In discussing this evidence and following from recommendation 1.5.32 about involving families in discharge planning, the committee wanted to ensure families and carers are given a copy of the discharge plan and that they know what will happen next. The committee agreed it was the hospital's responsibility to ensure this happens and also to ensure that the GP receives a copy of the plan. Due to the overlap with the NICE guideline on transition between hospital and home, the committee agreed to adapt a recommendation from that guideline. Recommendation 1.5.34 is based on committee discussions about transfer from hospital to a community setting, as in recommendations 1.5.32 and 1.5.33. The committee reached a consensus that following transfer from hospital the hospital learning disability liaison nurse should work together with community learning disability teams and primary care practitioners to provide ongoing support. Recommendation 1.5.35 was agreed through discussions around the principles of a good transfer of care from hospital. The committee felt strongly that the recommendations set out in the NICE guideline on transition between hospital and home should be followed for older people with learning disabilities so they specifically sign post practitioners to that guideline.

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Topic/section heading	**Care and support for people living with dementia**
Recommendations	1.5.36 Explain at an early stage to older people with learning disabilities (particularly people with Down's syndrome) and their family members or carers about the link between learning disabilities and dementia. Explain the signs of dementia, how it usually progresses and what support is available. Give people:

	- printed information on dementia - opportunities for one-to-one discussion with a professional - advice on communication strategies for people with dementia. 1.5.37 Commissioners should ensure information is provided to family members and carers of older people with learning disabilities who are being assessed for, or have been diagnosed with dementia. Consider also providing training. Information and training might cover: - types of dementia - how dementia might present in people with different learning disabilities - care pathways for different dementias - practical steps to manage daily life - communication skills - how to find further advice and ongoing support, including support groups and respite services.
Research recommendations	The Guideline Committee agreed the following research recommendation to address gaps in evidence about dementia training for families: Research recommendation 4 What is the effectiveness, cost effectiveness and acceptability of training programmes (for example in the use of life story work) for families of older people with learning disabilities who have dementia or are at risk of developing it?
Review questions	4a) What is the acceptability, effectiveness and cost effectiveness of providing information, advice, training and support for families, carers and advocates of older people with learning disabilities? 4b) What are the views and experiences of older people with learning disabilities and their carers about information, advice, training and support provided to families, carers and advocates? 4c) What are the views and experiences of health, social care and other practitioners about information, advice, training and support for families, carers and advocates?
Quality of evidence	Recommendations 1.5.36 and 1.5.37 are both based on evidence reviewed for question 4 about information, training and advice for families, carers and advocates of older people with learning disabilities. Four papers were reviewed for question 4 and they provided data about the views and experiences of older people with learning disabilities and their families although no data on practitioner views. Overall, the internal validity of the studies was judged to be moderate. The studies focused on gaps in information, training and support needs for carers of older people. There was a lack of evidence trialling approaches or interventions, and gaps in evidence about training programmes for older people with learning disabilities, in terms of how best to provide them and how effective they are.
Economic considerations	No economic evidence was identified. The guideline committee thought that training and information to persons, families and carers was particularly important for this population due to the

	very high prevalence. They thought that the dementia friendly practice was a good example of how training and information could be done and that they were likely to be cost-effective as they helped people to stay in their communities.
Evidence statements – numbered evidence statements from which the recommendations were developed	FCA2: There is a small amount of evidence that information about dementia and adults with learning disabilities is particularly lacking, leaving families uninformed and unprepared. The quality of the evidence is moderate. A UK study by Atkins and Loverseed (2012 +) found that families had little information about dementia and how it would progress. They did not know where to look for reliable information and ended up using informal sources, which often led to further confusion (p1). Another UK study (McLaughlin and Jones 2011 +) reported that the need for information was greatest before the person had been diagnosed with dementia and was generally not available. Following diagnosis, families needed specific information about the disease and its likely progress and impact (p5). (Recommendation1.5.36) FCA3: There is a small amount of evidence that support needs for families and carers of older people with learning disabilities and dementia are not being met. The quality of the evidence is moderate. The study by Atkins and Loverseed (2012 +) reported that some family carers were reluctant to ask for formal support because of past negative experiences with professionals and services (p1). The UK study by McLaughlin and Jones (2011 +) found that carers' support needs increased after the older person with a learning disability had been diagnosed with dementia, for example because of the increase in medical appointments. Families and carers needed to access respite services but did not know how (p5). The American study by Janicki et al. (2010 +) also found that carers had unmet needs from respite services (p4). (Recommendation 1.5.37) FCA5: There is a small amount of evidence that some family carers of older people with learning disabilities need specialist training, particularly in relation to additional conditions. The quality of the evidence is moderate. The study by Atkins and Loverseed (2012 +) found that carers wanted professional advice about how to communicate with the older person with a learning disability and this was particularly following a dementia diagnosis (p1). The study by Janicki et al. (2010 +) also found that family carers wanted training on specialist dementia care to help them provide the right support (p4). (Recommendation 1.5.37)
Other considerations	Recommendation 1.5.36 is based on FCA2 which reports that due to a lack of available information, families feel ill prepared to support older people with learning disabilities and dementia. Families cited in the research did not know where to look for information and needed advice about specifics such as how to communicate with the person. The committee therefore the recommendation that practitioners should explain to families at an early stage about the link between learning disabilities and dementia. Printed information and advice about communication should also be provided as well as opportunities for one to one discussions.

	Recommendation 1.5.37 is based on evidence in FCA3 that families of older people with learning disabilities and dementia are not given adequate support. Support needs were particularly acute following a dementia diagnosis. The recommendation is also supported by FCA5 which reports that families of older people with learning disabilities need specialist training and information and the evidence specifically related to dementia support. The committee therefore agreed a recommendation to ensure that families are provided with information about certain aspects such as communication skills and likely care pathways. The committee also wished to recommend training for carers of people with learning disabilities and dementia but since this was only cited in one moderate quality study (Janicki et al. 2010 +) they agreed this element should be weaker, hence use of the phrase 'consider training'. In light of this the committee also agreed to develop a research recommendation on dementia education and training for families in order to provide evidence for stronger recommendations in future.

Topic/section heading	**End of life care - access to end of life care services**
Recommendations	1.6.1 Give older people with learning disabilities and their family members and carers accessible information about all the potential care options available for end of life care, including hospice services. 1.6.2 Practitioners providing end of life care should spend time getting to know the person to understand their needs. Get to know how they communicate, their cultural background, what they like and dislike, how they express pain, their health conditions and the medication they are taking. Be aware that this understanding will make it easier to identify when the person's health is deteriorating. 1.6.3 Identify who the person would like to involve in creating their end of life plan. Include the person themselves and everyone who supports them in discussions and planning. 1.6.4 Ask the person regularly who they would like to involve in discussions about their end of life plan, in case they change their mind. Do this every 6 months or more often if the person is close to the end of life. 1.6.5 Make it possible for the person to die where they wish. This might include adapting their home, working with other practitioners and advocates, and talking to other residents or family members about changes that could be made (for example, moving the person to a room on the ground floor).
Research recommendations	The Guideline Committee agreed the following research recommendations to address gaps in evidence about the advance planning for end of life care and care and support at the end of life: Research 5

	a) What is the effectiveness and cost effectiveness of advance care planning about end of life care for older people with learning disabilities, and their family members and carers? b) What processes are in place to document and follow the wishes of older people with learning disabilities about their decisions on end of life care? Research recommendation 8 a) What is the effectiveness and cost effectiveness of end of life care for older people with learning disabilities? b) What can mainstream health and social care services do to support older people with learning disabilities and their primary carer (both family and paid carers) at the end of life?
Review questions	8a) What is the effectiveness and cost effectiveness of end of life care for older people with learning disabilities? 8b) What are the views and experiences of older people with learning disabilities and their carers in relation to end of life care? 8c) What are the views and experiences of health, social care and other practitioners about support for older people with learning disabilities at the end of life?
Quality of evidence	Recommendations 1.6.1, 1.6.2, 1.6.3, 1.6.4 and 1.6.5 are all based on evidence reviewed for question 8 about end of life care, which included 11 papers. There was limited evidence about the views and experiences of older people with learning disabilities and their families (n=2) and no effectiveness or cost-effectiveness evidence. The 9 studies providing practitioner views were low to moderate in terms of internal validity.
Economic considerations	No economic evidence was identified. For the general population, access to better end of life care has been linked to reduced (emergency) hospital admissions and cost savings, and it is possible that this relationship is also true for people with learning disabilities. In addition, supporting people to die in the place they wish to die can lead to fewer deaths in hospital, which are more costly than deaths in the usual place of residence. Evidence for the general population showed that advance care panning might facilitate those outcomes (and potential cost savings).
Evidence statements – numbered evidence statements from which the recommendations were developed	EL1: There is a small amount of evidence that older people with learning disabilities want equal access to end-of life care services, including access to support and comprehensive information about their condition. The quality of the evidence is moderate. McLaughlin (2014a +) found that people with learning disabilities and their family carers expressed a need to improve access to and be given information about end of life care services. (Recommendation 1.6.1) EL5: There is some evidence about the importance of person centred care for people with learning disabilities at the end of their lives. The quality of the evidence is moderate. McCarron (2010 +) found that disability service staff felt that knowing the person's likes/ dislikes were seen as being central to good dementia care. Respondents felt that learning disability services have a strong philosophy of person centred care. Morton-Nance (2012 +) found that community nurses reported positive experiences when palliative care was person centred and included good planning,

	preparation, outreaching and sharing of information with other healthcare professionals. Cartlidge (2010 −) reported that staff felt it was very important to get to know people with learning disabilities and to build up trust and confidence when caring for them at the end of their lives. (Recommendations 1.6.2 and 1.6.5) EL9: There is a small amount of evidence that professionals believe a 'good death' means spending time with the person until the end. The quality of the evidence is moderate. McCarron et al (2010 +) reported that learning disability staff described the importance of paying attention to the detail of providing a 'good death'. For example, spending time with the person, ensuring the person does not die alone. Todd (2013 +) found that residential staff perceived that 'being there' through the transition from living to dying and being able to remember the person after their death was important. 'Good deaths' were deaths that allowed staff to express 'being there', despite the emotional pain and impact of the death on staff. (Recommendation 1.6.3 and 1.6.4)
Other considerations	Recommendation 1.6.1 is based on EL1 which reported that older people with learning disabilities and their families want better access to information about end of life care. On this basis the committee recommended that accessible information about all end of life care options is made available to older people with learning disabilities and their families. Recommendation 1.6.2 is based on EL5 about the importance of person centred end of life care for older people with learning disabilities. The committee agreed about the importance of getting to know people, understanding their likes and dislikes and their preferred means of communication, especially during the end of life phase. They therefore agreed the recommendation that practitioners should spend really getting to know the individual. Recommendation 1.6.3 is based on EL9 which reports that residential staff though they or someone familiar ought to be with the person when they die and this would ensure a good death. In discussing this evidence the committee felt that people would all have different ideas about what a good death would look like. Therefore they recommended that older people with learning disabilities should identify who they want to have involved in planning for the end of life. They also recognised that people's preference may change over time so they also agreed 1.6.4 to ensure that people can change their minds about who they would like to have involved in end of life discussions. There were lengthy discussions about how often people's preferences should be reviewed and committee agreed that every 6 months would strike a good balance although it should be more often if they are very close to the end of life. Recommendation 1.6.5 is based on EL5 about the importance of person centred care at the end of life and also EL6 which found that practitioners believe older people with learning disabilities should be supported to die in their usual place of residence. The committee agreed it is important to ensure people die where they wish to and they discussed actions that may need to be taken to ensure this. The experts by experience said that one way would be to swap bedrooms to make it easier to provide the necessary

	care during the end of life. They also said that if a person in a group home was at the end of life, it would help to talk to other residents to discuss what changes they think could be made to accommodate the dying person.

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Topic/section heading	**End of life care - involving families and support networks**
Recommendations	1.6.6 During end of life care planning, talk to the person and their family members and carers to understand the person's wishes and any cultural needs at the end of the person's life. 1.6.7 When providing end of life care, learn from family members and carers about the person's needs and wishes, including those associated with faith and culture, nutrition, hydration and pain management. This is particularly important if the person is unable to communicate. 1.6.8 Learning disability providers delivering care at the end of life should work collaboratively and share information with other practitioners and services involved in the person's daily life . 1.6.9 Social care providers should work in partnership with healthcare providers to share knowledge about the person and to develop expertise for end of life care. 1.6.10 Provide training, information and support for family members and carers, for example in medication, pain, nutrition and hydration, to enable the person to die where they wish to. 1.6.11 Make sure that key people in the support network have the knowledge, confidence and understanding to communicate with the person about their illness and death. This includes discussion about symptoms, pain management and preferences about resuscitation. 1.6.12 Mainstream end of life care services should make reasonable adjustments to support the person, their family members, friends and carers and other people they live with throughout palliative and end of life care and bereavement. 1.6.13 For further guidance on end of life care see NICE's guideline on care of dying adults in the last days of life.
Research recommendations	The Guideline Committee agreed the following research recommendations to address gaps in evidence about advance planning for end of life and care and support at the end of life: Research 5 a) What is the effectiveness and cost effectiveness of advance care planning about end of life care for older people with learning disabilities, and their family members and carers? b) What processes are in place to document and follow the wishes of older people with learning disabilities about their decisions on end of life care? Research recommendation 8 a) What is the effectiveness and cost effectiveness of end of life care for older people with learning disabilities?

	b) What can mainstream health and social care services do to support older people with learning disabilities and their primary carer (both family and paid carers) at the end of life?
Review questions	8a) What is the effectiveness and cost effectiveness of end of life care for older people with learning disabilities? 8b) What are the views and experiences of older people with learning disabilities and their carers in relation to end of life care? 8c) What are the views and experiences of health, social care and other practitioners about support for older people with learning disabilities at the end of life?
Quality of evidence	Recommendations 1.6.6, 1.6.7, 1.6.8, 1.6.9, 1.6.10, 1.6.11, 1.6.12 and 1.6.13 are all based on evidence reviewed for question 8 about end of life care, which included 11 papers. There was limited evidence about the views and experiences of older people with learning disabilities and their families (n=2) and no effectiveness or cost-effectiveness evidence. The 9 studies providing practitioner views were low to moderate in terms of internal validity.
Economic considerations	No economic evidence was identified. The guideline committee thought that including the carer, family and support network was an important part of cost-effective care from a government budget perspective. In particular, they thought that activities carried out by the carer, family and support network would otherwise require much more costly involvement from professionals. Examples they provided included helping managing medication, hydration and nutrition.
Evidence statements – numbered evidence statements from which the recommendations were developed	EL5: There is some evidence about the importance of person centred care for people with learning disabilities at the end of their lives. The quality of the evidence is moderate. McCarron (2010 +) found that disability service staff felt that knowing the person's likes/ dislikes were seen as being central to good dementia care. Respondents felt that learning disability services have a strong philosophy of person centred care. Morton-Nance (2012 +) found that community nurses reported positive experiences when palliative care was person centred and included good planning, preparation, outreaching and sharing of information with other healthcare professionals. Cartlidge (2010 −) reported that staff felt it was very important to get to know people with learning disabilities and to build up trust and confidence when caring for them at the end of their lives. (Recommendation 1.6.6) EL3: There is a small amount of evidence based on views and experiences data that end of life care would be improved if professionals worked more closely with family carers and people with learning disabilities. The quality of the evidence is moderate. In the UK study by McLaughlin et al. (2014a +) people with learning disabilities and their family carers said that doctors, nurses and other professionals needed to work more closely with them and learn from them about ways of improving end of life care. They also emphasized the importance of a holistic family-centred approach in end of life care, with professionals working together with families to achieve this. In McCarron et al. (2010 +) disability service staff said that keeping links with family to maintain relationships was important, especially for people with

	learning disabilities and dementia throughout the continuum/ progress of dementia. (Recommendation 1.6.7) EL4: There is a good amount of evidence, from views and experience studies, that better collaborative working between professionals would improve end of life care for people with learning disabilities. The quality of the evidence ranges from low to moderate. In Morton-Nance and Schafer (2012 +) district nurses emphasised the importance of effective collaborative working and sharing of expertise across disciplines to improve end of life services for people with learning disabilities. The nurses also said that difficulties in communication between healthcare professionals created barriers to good quality end of life care. McLaughlin et al. (2014b +) reported that specialist palliative services highlighted the benefits of joint working and learning between services as a way of generating trust, improving communication and ending isolation between services. In Bailey et al (2016 −) community nurses emphasised the benefits of liaison between family and professional and nonprofessional carers, and collaborative working to promote the development of mutual understanding as to when and how to involve each other in the care process. This was seen as crucial for ensuring optimal end of life care for people with learning disabilities. Cross et al. (2012 −) highlighted problems when joint working does not occur: ‘the project mostly involved direct health and social care professionals, trainers, and voluntary sector organizations, not system managers and not local users and family carers. This might explain some of the problems experienced in partnership working’. In McCarron et al. (2010 +) learning disability staff said they needed support with palliative care so that people could die in their home. Also, a more collaborative approach would be welcomed, where a service can consult with specialist palliative care services on pain management and symptoms. In Ryan et al. (2010 +) palliative care and learning disability staff said that any problems with end of life care could be overcome if they worked in partnership. However there was no evidence that this collaboration ever happened. (Recommendation 1.6.8 and 1.6.9) EL6: There is some evidence that health professionals believe people with learning disabilities should be supported to die in their usual place of residence, not least because of the familiar and peaceful environment. The quality of the evidence is moderate. In McLaughlin et al. (2014b +) specialist palliative professionals said the person with learning disabilities should have the option to die in their familiar place of care. McCarron (2010 +) reported that most learning disability staff agreed the ideal place for end of life care was a person’s own home although they recognised this is not always possible because staff sometimes lack specialist knowledge. In the Todd study (2013 +) residential staff felt that the residential home was the most appropriate place of death for the person with a learning disability. (Recommendation 1.6.10) EL7: There is a moderate amount of evidence that certain professionals (nurses and learning disability staff) felt they lack the knowledge, skills and confidence to manage end of life care for people with learning disabilities, in aspects such as resuscitation, pain and symptom management and

	communication. The quality of the evidence is moderate. In Bailey (2016 −) community nurses said their lack of knowledge, understanding, confidence, communication skills and resources were the main barriers preventing them providing end of life care to people with learning disabilities. According to Cartlidge (2010 −) hospice staff found it difficult to discuss patients' health status and treatment compliance issues with them. It was hard to make them understand their conditions and also difficult to gain valid consent. They said it was hard to get to know the patient and adjust communication to suit their individual needs. In McCarron et al. (2010 +) learning disability staff said they lacked knowledge and needed guidance around issues such as pain and symptom management, resuscitation and maintaining adequate hydration and nutrition. They were open to specific training in these areas. In Morton-Nance and Schafer (2012 +) community nurses identified a number of barriers to providing good quality end of life care for people with learning disabilities. These included health professionals' inexperience and lack of understanding, skills and training, which make it difficult to meet patients' basic needs. In Ryan et al (2010 +) palliative care staff said that although they were willing, they felt unable to provide end of life care to people with learning disabilities due to their own lack of knowledge. Similarly learning disability staff said their training about end of life care had been inadequate. (Recommendation 1.6.11) EL10: There is a small amount of evidence that family carers of older people with learning disabilities need information and bereavement support, which is currently lacking. The quality of the evidence is moderate. In McLaughlin et al (2014a +) family carers of people with learning disabilities who are at the end of their lives said they need bereavement support from a counsellor. (Recommendation 1.6.12)
Other considerations	Recommendation 1.6.6 is based on EL5 about the importance of person centred care at the end of life for older people with learning disabilities. The committee agreed about the importance of these findings and therefore developed the recommendation that practitioners talk to the person and their families to ascertain their wishes and preferences, including any cultural needs Recommendation 1.6.7 is based on EL3 which reported that end of life care for older people with learning disabilities would be improved if practitioners worked more closely with families and next of kin. The committee therefore agreed this recommendation to emphasise the importance of involving families and discussing certain issues. They emphasised that this is especially important if the dying person is unable to communicate. Recommendation 1.6.8 is based on evidence in EL4 that end of life care for older people with learning disabilities would be improved by closer working between professionals. This resonated with the experience of the committee so on this basis they recommended that providers should work collaboratively and sharing information as they provide end of life care. Recommendation 1.6.9 is also based on EL4 about the importance of collaborative working around the provision of end of life care. The committee focused on the evidence that

	collaborative working provided opportunities for sharing knowledge about the person and developing expertise in the provision of end of life care. They therefore recommended that social care and health practitioners work in partnership. Recommendation 1.6.10 is based on EL6 that reported that health practitioners felt people should be supported to die in their usual place of residence. The committee agreed with this although they that it could only be achieved if staff – or families, depending on the person's place of residence – are provided with training in key areas such as pain management, nutrition and hydration. Recommendation 1.6.11 is based on EL7 which found that practitioners felt ill prepared to provide adequate end of life care for older people with learning disabilities. The committee felt this would apply to people in the support network in general and that practitioners should therefore work with them to ensure they feel able communicate with the person about end of life care. This should include asking about sensitive issues such as preferences for resuscitation. Recommendation 1.6.12 is based on EL10 which reports a small amount of evidence that family carers of older people with learning disabilities need information and bereavement support. The committee agreed this was an important issue and in their experience, felt that the unmet need actually applies more widely given that older people with learning disabilities may be living in group homes. Therefore the committee agreed that as well as fmailies, other people living with the person should be supported throughout the palliative and end of life phases. They emphasises that reasonable judgements may be required to provide this support. Finally, the guideline committee agree to refer practitioners to the NICE guideline on care of dying adults, hence 1.6.13. They felt that all the recommendations in that guideline ought to be followed for older people with learning disabilities.
Topic/section heading	**Workforce skills and expertise**
Recommendations	1.7.1 Managers in health and social care services should ensure that staff in older people's services have the expertise to support older people with learning disabilities from a wide range of backgrounds. 1.7.2 Managers in health and social care services should ensure that learning disability staff have the skills and understanding to support people's changing needs as they grow older. Provide this skilled support in all settings, including people's own homes. 1.7.3 Managers in health and social care services should ensure that all staff working with older people with learning disabilities have skills and knowledge in:

	• communication methods, including non-verbal communication • building good relationships with people with learning disabilities and making them feel at ease • the physical and mental health needs of older people with learning disabilities, related to both their age and disability • common health conditions to which older people with learning disabilities are predisposed, for example the earlier onset of dementia, ensuring that they do not confuse these with the person's learning disability or another condition 1.7.4 Managers in health and social care services should provide opportunities for learning disability staff and practitioners working with older people to share expertise with each other as part of their knowledge and skills development. 1.7.5 Staff should know what local services are available (including housing options) so they can support older people with learning disabilities, families, carers and advocates to make informed choices about their care and support.
Research recommendations	The Guideline Committee agreed the following research recommendations to address gaps in evidence about the identification of health conditions, self management of health conditions, dementia training for families, care and support at home and tele-monitoring: Research recommendation 1 What is the effectiveness and cost effectiveness of care and support models (for example, assistive technology) for older people with learning disabilities to enable them to live at home with or without their family? Research recommendation 2 a) What is the effectiveness and cost effectiveness of different ways of identifying age-related and other physical and mental health conditions, in older people with learning disabilities? b) What can mainstream and specialist health services do to facilitate: - early identification of health conditions in older people with learning disabilities? - equal access to health services in older people with learning disabilities? Research recommendation 3 What is the effectiveness and cost effectiveness of education programmes to improve information and advice and to support self-management of chronic health conditions (for example obesity, diabetes and cardiovascular disease) for older people with learning disabilities and their family members and carers? Research recommendation 4 What is the effectiveness, cost effectiveness and acceptability of training programmes (for example in the use of life story work) for

	families of older people with learning disabilities who have dementia or are at risk of developing it? Research recommendation 7 a) What is the effectiveness and cost effectiveness of telemonitoring for older people with learning disabilities in: - promoting understanding and improving management of chronic physical and mental health conditions? - supporting their ageing family carers to continue providing care? b) What are the mechanisms that make telemonitoring accessible and acceptable to older people with learning disabilities?
Review questions	1. What are the views and experiences of older people with learning disabilities and their carers about how care and support needs are identified, assessed and reviewed? 2. What are the views and experiences of health, social care and other practitioners about how the health and social care needs of older people with learning disabilities and their carers are identified, assessed and reviewed? 3a) What is the acceptability, effectiveness and cost effectiveness of providing information, advice and training to older people with learning disabilities? 3b) What are the views and experiences of older people with learning disabilities and their carers about information, advice and training to older people with learning disabilities? 3c) What are the views and experiences of health, social care and other practitioners about information, advice and training to older people with learning disabilities? 4a) What is the acceptability, effectiveness and cost effectiveness of providing information, advice, training and support for families, carers and advocates of older people with learning disabilities? 4b) What are the views and experiences of older people with learning disabilities and their carers about information, advice, training and support provided to families, carers and advocates? 4c) What are the views and experiences of health, social care and other practitioners about information, advice, training and support for families, carers and advocates? 5a) What is the acceptability, effectiveness and cost effectiveness of interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 5b) What are the views and experiences of older people with learning disabilities and their carers about interventions or approaches to improve access and referral to health, social care and housing support services? 5c) What are the views and experiences of health, social care and other practitioners about interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities? 7a) What is the acceptability, effectiveness and cost effectiveness of care and support at home, in supported housing and in

	accommodation with care and support for older people with learning disabilities? 7b) What are the views and experiences of people using services and their carers in relation to care at home, in supported housing or accommodation with care and support for older people with learning disabilities? 7c) What are the views and experiences of health, social care and other practitioners about care and support at home, in supported housing or accommodation with care and support for older people with learning disabilities? 9a) What are the views and experiences of older people with learning disabilities and their carers about care and support in health settings? 9b) What are the views and experiences of health, social care and other practitioners about the care and support of older people with learning disabilities in health settings?
Quality of evidence	Recommendation 1.7.1 and 1.7.2 are both based on evidence reviewed for questions 1 and 2 about the identification, assessment and review of care and support needs among older people with learning disabilities. Due to the overlap with the NICE guideline on older people with social care needs and multiple long term conditions, the recommendation was adapted from that guideline. For question 1, there were 7 studies, which on average were moderate in terms of their internal validity. Only 1 study of moderate quality specifically answered question 2 and a further 4 studies provided data to answer both questions 1 and 2 because they reported practitioner views as well as views of older people with learning disabilities and their carers or families. There were gaps in the evidence about assessment and review of needs, with most of the data covering future planning. The gaps in the data led to discussions based on committee expertise, with crucial input from the experts by experience, including carers. Recommendation 1.7.3 is based on evidence reviewed for review question 9 about experiences in health settings for older people with learning disabilities. Overall, for question 9, 6 studies were located and they were moderate to good in terms of internal validity. Practitioner, service user and family views were all represented, providing useful insight into the experiences and preferences of older people with learning disabilities in relation to health assessments and interaction with practitioners although there were clear gaps in evidence about the perspective of health practitioners e.g. hospital practitioners or GPs. Is it also supported by evidence reviewed for question 3 about information, training and advice for older people with learning disabilities. A total of 6 papers were included for this question and overall, their internal validity was good to moderate. Only one effectiveness study was found, although the results were of limited use due to methods issues. The views and experiences or older people with learning disabilities and their families were well represented in the evidence but only one study provided the practitioner perspective. The views studies provided important information about what works and what does not in providing information. There was a particular lack of evidence trialling approaches or interventions,

	and a gap in evidence about training for older people with learning disabilities, whether it is needed and how best to provide it. Finally recommendation 1.7.3 is also supported by evidence reviewed for question 4 about information, training and advice for families, carers and advocates of older people with learning disabilities. Four papers were reviewed for question 4 and they provided data about the views and experiences of older people with learning disabilities and their families although no data on practitioner views. Overall, the internal validity of the studies was judged to be moderate. The studies focused on gaps in information, training and support needs for carers of older people. There was a lack of evidence trialling approaches or interventions, and gaps in evidence about training programmes for older people with learning disabilities, in terms of how best to provide them and how effective they are. Recommendation 1.7.5 is based on evidence reviewed for question 5 about access and referral to health, social care and housing services. The evidence located for review question 5 (n=7) was moderate to good in terms of internal validity and provided data on the views and experiences of older people with learning disabilities, their families and carers and also of practitioners. There was no effectiveness evidence and the views and experiences data focussed on barriers to access rather than means of improving access and referral. Recommendations 1.7.4 and 1.7.5 are both based on evidence reviewed for question 7 about care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities. A total of 8 papers were reviewed for this question although there was very little effectiveness evidence, with data found in just 1 study. Data on views and experiences were mainly from the practitioner perspective (n=5), on supporting adults with learning disabilities in group homes as they grow older and supporting adults with learning disabilities in residential care for older people. There were gaps in evidence about the effectiveness and experiences of care and support in the family home, which had implications for developing recommendations and drawing on other evidence, in particular expert testimony.
Economic considerations	No economic evidence was identified. The guideline committee thought that the only affordable solution in the long-term was to ensure that standard health and social care and other mainstream services were able to address the needs of this increasing population. Whilst the guideline committee agreed that some people with severe needs would always need specialist support (defined as in services provided by staff with specialist knowledge in ageing as well as in learning disability), this could not be a cost-effective solution for the majority of people. Instead, a stepped care approach was seen as cost-effective, which ensured that people accessed the right level of care according to their needs. This included access to mainstream health and social care, which was seen as appropriate for the majority of people with mild to moderate learning disabilities.

Evidence statements – numbered evidence statements from which the recommendations were developed	IAR1: There is a small of good quality evidence that practitioners supporting adults with learning disabilities feel they cannot continue to provide care throughout the person's 'old' age. One good quality study (Bigby et al. 2011 ++) found that when a person's medical or personal care needs reached a certain level they would have to move to an aged care environment. The point at which their needs reached this level was subjective and variable and it was hard for families to anticipate. (Recommendation 1.7.1) HS1: There is a small amount of evidence that health practitioners do not communicate well with older people with learning disabilities, resulting in poor health care experiences. One study (Webber et al. 2010 ++) reported a particular concern among carers was a lack of, or inappropriate communication from hospital staff, for example when talking to patients about treatment they could not understand. Practitioners also failed to take time to interact with older people with learning disabilities. This could lead to misunderstandings (p8). Another study (Fender et al. 2007 ++) reported that older people with learning disabilities agreed that doctors should be sensitive about the questions they ask people during examinations. They also recommended ways that doctors can diagnose problems when a person is unable to communicate (p3). (Recommendation 1.7.3) HS2: There is a small amount of evidence that health practitioners lack understanding about the needs of older people with learning disabilities. A good quality study by Webber (2010 ++) found, that in the experience of carers, hospital practitioners seemed uncomfortable and inexperienced with older people with learning disabilities. This resulted in unmet personal care needs and poor communication. It also led to a lack of sensitivity about the importance of following people's personal routines and pain management plans. This lead to disruptive behaviour. In the worst cases, carers felt that this lack of understanding resulted in premature transfer from hospital and pressure on group homes to accept the resident following discharge (p8). Northway et al. (2016 +) found that when health practitioners respected the special insight that managers of supported living schemes have into residents' changing health needs, this provides a basis for effective joint working to address those needs. (Recommendation 1.7.3) IAT5: There is a small amount of evidence that practitioners could play a greater role in providing advice and support about health issues to older people with learning disabilities. The quality of the evidence is moderate to good. The UK study by Young (2012 ++) found that older people with learning disabilities really value the medical knowledge and authority of health professionals. However health professionals themselves often do not recognise the important contribution they can make in supporting people to manage their conditions (p6). The Willis study (2010 +) reported that care workers wanted more training so that they would be able to provide better support and advice to older women with learning disabilities while they experience the menopause (p8). (Recommendation 1.7.3)

	FCA2: There is a small amount of evidence that information about dementia and adults with learning disabilities is particularly lacking, leaving families uninformed and unprepared. The quality of the evidence is moderate. A UK study by Atkins and Loverseed (2012 +) found that families had little information about dementia and how it would progress. They did not know where to look for reliable information and ended up using informal sources, which often led to further confusion (p1). Another UK study (McLaughlin and Jones 2011 +) reported that the need for information was greatest before the person had been diagnosed with dementia and was generally not available. Following diagnosis, families needed specific information about the disease and its likely progress and impact (p5). (Recommendation 1.7.3) H2: There is a moderate amount of good quality evidence that staff lack the expertise and understanding to support older people with learning disabilities in their home environment. The study by Kåhlin et al. (2015 ++) found that staff in a learning disability group home tended not to address the issue of ageing directly with residents and found it hard to distinguish symptoms of ageing from symptoms of the development of the learning disability (p12). Iacono (2014 ++) found that staff in a learning disability group home did not necessarily have specific training or knowledge about older people with learning disabilities, instead dealing with them in an ad hoc manner, and they doubted their organisation's commitment to providing the required support to keep them in place long term (p10). Bigby et al. (2008 ++) found that one of the difficulties in supporting older people with learning disabilities in a residential setting for older people was a lack of training among staff. Respondents also explained that when older people with learning disabilities did not participate in activities, this could be because of emotional or behavioural difficulties, which suggests staff may not be sufficiently experienced to deal with these (p7). Maes and Van Puyenbroeck (2008 +) found that not many staff in residential services had received training in supporting older people with learning disabilities (p14). (Recommendations 1.7.4 and 1.7.5) AR4: There is some evidence that a lack of awareness and understanding among practitioners about supporting older people with learning disabilities has the effect of reducing access to support. The quality of the evidence is good. Research in rural Australia (Wark et al. 2015 ++) showed that having a GP who knows the older person with a learning disability, understands their needs and can communicate well was a key aspect of providing access to health care and ensuring a 'good life' (p5). A Northern Ireland study (McIlfatrick et al. 2011 ++) found that health professionals have an important role in explaining breast examinations to women with learning disabilities and that this promotes access by putting them at ease and encourages them to attend appointments (p15). Similarly in a US study (Swaine et al 2013 ++) family carers believed that having a doctor who is competent with facilitating learning disabilities and explains a medical procedure in advance helped women with learning disabilities to access breast exams (p3). (Recommendation 1.7.5)

Other considerations	Recommendation 1.7.1 and 1.7.2 are both based on IAR1 which reported a small amount of evidence that practitioners supporting adults with learning disabilities do not feel they can provide adequate support during the person's old age. In discussing the evidence the committee agreed there is insufficient sharing of expertise between learning disability and older people's services. Therefore in 1.7.1 they recommended that managers ensure practitioners in older people's services have the expertise to support people with learning disabilities and in 1.7.2 they recommended that practitioners in learning disability services (in all settings) have the skills to support people's changing needs as they grow older. Recommendation 1.7.3 is based on a body of evidence highlighting important skills that practitioners should have if they are supporting older people with learning disabilities. Evidence statements HS1 and HS2 highlighted that practitioners often lack understanding about people with learning disabilities and in particular they have difficulty in knowing how best to communicate. IAT5 and FCA2 highlighted that evidence about people with learning disabilities and dementia is lacking and that older people with learning disabilities trust practitioners to provide them with information and advice. The committee therefore felt it was important for practitioners to have specific knowledge in order to be able to impart information and provide adequate support. They agreed that this should apply to all staff working with people with learning disabilities even though the evidence seemed to focus on health practitioners. Recommendation 1.7.4 is based on H2 which reported that learning disability staff lack the skills to support older people and staff in older people's services lacked training to work with people with learning disabilities. Therefore the committee agreed the recommendation that opportunities should be provided for all staff to share expertise and skills. Recommendation 1.7.5 is also based on discussions about H2. The committee felt that gaps in knowledge and understanding are highlighted during the transition into 'older age'. They wanted to ensure that staff in learning disability services have a good understanding of local services so that they can support people to make informed choices as they grow older.

Topic/section heading	**Workforce skills and expertise for supporting end of life care**
Recommendations	1.7.6 Commissioners and providers of end of life care should recognise the complex needs of older people with learning disabilities. They should provide ongoing training for staff to ensure they have the expertise to provide good-quality coordinated care, enabling people to die in their own home or another place of their choice. Training should include:

	- having discussions about resuscitation intentions - finding out and responding to cultural preferences - managing symptoms, pain and medication - nutrition and hydration - understanding communication preferences and being able to communicate – this might include using an augmentative communication system. 1.7.7 Provide in-service training for learning disability and palliative care practitioners so they have the skills to support people at the end of life. This might include joint study days and training of professionals by people with learning disabilities and their family members and carers.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	8a) What is the effectiveness and cost effectiveness of end of life care for older people with learning disabilities? 8b) What are the views and experiences of older people with learning disabilities and their carers in relation to end of life care? 8c) What are the views and experiences of health, social care and other practitioners about support for older people with learning disabilities at the end of life?
Quality of evidence	Recommendations 1.7.6 and 1.7.7 are based on evidence reviewed for question 8 about end of life care, which included 11 papers. There was limited evidence about the views and experiences of older people with learning disabilities and their families (n=2) and no effectiveness or cost-effectiveness evidence. The 9 studies providing practitioner views were low to moderate in terms of internal validity.
Economic considerations	No economic evidence was identified. There is evidence for the general population that access to better end of life care can reduce (emergency) hospital admissions. Helping people to die in their preferred place of death was likely to lead to fewer deaths in hospital, which are more costly than deaths in the usual residence (such as home and care home).
Evidence statements – numbered evidence statements from which the recommendations were developed	EL4: There is a good amount of evidence, from views and experience studies, that better collaborative working between professionals would improve end of life care for people with learning disabilities. The quality of the evidence ranges from low to moderate. In Morton-Nance and Schafer (2012 +) district nurses emphasised the importance of effective collaborative working and sharing of expertise across disciplines to improve end of life services for people with learning disabilities. The nurses also said that difficulties in communication between healthcare professionals created barriers to good quality end of life care. McLaughlin et al. (2014b +) reported that specialist palliative services highlighted the benefits of joint working and learning between services as a way of generating trust, improving communication and ending isolation between services. In Bailey et al (2016 −) community nurses emphasised the benefits of liaison between family and professional and nonprofessional carers, and collaborative working to promote the development of

	mutual understanding as to when and how to involve each other in the care process. This was seen as crucial for ensuring optimal end of life care for people with learning disabilities. Cross et al. (2012 −) highlighted problems when joint working does not occur: ‘the project mostly involved direct health and social care professionals, trainers, and voluntary sector organizations, not system managers and not local users and family carers. This might explain some of the problems experienced in partnership working’. In McCarron et al. (2010 +) learning disability staff said they needed support with palliative care so that people could die in their home. Also, a more collaborative approach would be welcomed, where a service can consult with specialist palliative care services on pain management and symptoms. In Ryan et al. (2010 +) palliative care and learning disability staff said that any problems with end of life care could be overcome if they worked in partnership. However there was no evidence that this collaboration ever happened. (Recommendation 1.7.6) EL7: There is a moderate amount of evidence that certain professionals (nurses and learning disability staff) felt they lack the knowledge, skills and confidence to manage end of life care for people with learning disabilities, in aspects such as resuscitation, pain and symptom management and communication. The quality of the evidence is moderate. In Bailey (2016 −) community nurses said their lack of knowledge, understanding, confidence, communication skills and resources were the main barriers preventing them providing end of life care to people with learning disabilities. According to Cartlidge (2010 −) hospice staff found it difficult to discuss patients' health status and treatment compliance issues with them. It was hard to make them understand their conditions and also difficult to gain valid consent. They said it was hard to get to know the patient and adjust communication to suit their individual needs. In McCarron et al. (2010 +) learning disability staff said they lacked knowledge and needed guidance around issues such as pain and symptom management, resuscitation and maintaining adequate hydration and nutrition. They were open to specific training in these areas. In Morton-Nance and Schafer (2012 +) community nurses identified a number of barriers to providing good quality end of life care for people with learning disabilities. These included health professionals' inexperience and lack of understanding, skills and training, which make it difficult to meet patients’ basic needs. In Ryan et al (2010 +) palliative care staff said that although they were willing, they felt unable to provide end of life care to people with learning disabilities due to their own lack of knowledge. Similarly learning disability staff said their training about end of life care had been inadequate. (Recommendation 1.7.6) EL8: There is a moderate amount of evidence that in-service training and education in palliative care would improve the quality of support for people with learning disabilities at the end of life. The quality of the evidence is mixed, ranging from low to moderate. The majority of community nurses (65-75%) surveyed in Bailey et al (2016 −) identified in-service education and workshops as a means to support their educational needs and suggested lectures and workshops (70%) as their preferred mode

	of delivery. Morton-Nance (2012 +) reported that community nurses wanted training in palliative care at all levels and emphasised the importance of effective collaborative working and sharing of expertise across disciplines. McLaughlin (2014b +) identified that the education and training needs of specialist palliative professionals, in the form of regional meetings, and joint 'study days', would be welcome and were felt to be a means of improving end of life care for people with learning disabilities. Cross (2012 −) found that home care staff made good use of the training sessions provided by the project. Learning disability community teams also benefited and were better informed about palliative care although views were mixed about whether it benefited palliative care professionals. The most appreciated aspects about the training were: reflecting on complex issues, thinking about difference, and facing fears. (Recommendation 1.7.7).
Other considerations	Recommendation 1.7.6 is based on EL4 and EL7, which reported evidence that better collaborative working between practitioners would improve end of life care and that certain practitioners lack the skills and confidence to manage end of life care for older people with learning disabilities. To address these problems, which resonated with members' expertise, the committee recommended that commissioners and providers of end of life care ensure practitioners are trained in a range of specific skills. Recommendation 1.7.7 is based on EL8 which reported that in service training and education in palliative care would improve the experience of end of life care for older people with learning disabilities. The committee therefore agreed a recommendation to ensure in service training for palliative care staff so they have the skills to support older people with learning disabilities at the end of life.

4 Implementation: getting started

Some issues were highlighted that might need specific thought when implementing the recommendations. These were raised during the development of this guideline. They are:

- Ensuring integrated, person-centred care and support for older people with learning disabilities, and their family and carers. This will mean health and social care practitioners and providers ensuring that they involve and listen to the person and their family/carers, and agree a care plan that reflects their needs and aspirations. It will also mean challenging assumptions and looking beyond the person's learning disability, to provide the support needed to live an active, community-involved life.

- Ensuring a well-trained and supported workforce, with the knowledge needed to support older people with learning disabilities. The structure of health and social care services tends to mean that practitioners are in either learning disability or older people's services, with training and support that reflects this. Moving to a workforce with expertise from across both disciplines may be challenging to achieve.
- Planning and commissioning local health and social care services to meet the needs of the population of older people with learning disabilities. Commissioners need to understand the extent of their population of older people with learning disabilities, and to be aware of any likely growth in numbers. Learning disability services are often seen as separate from the range of other services, but all pathways of care and support must consider the needs of older people with a learning disability in order to improve access and funding.

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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

Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence NICE guideline CG76 (2009)

Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services NICE guideline CG136 (2011)

Patient experience in adult NHS services: improving the experience of care for people using adult NHS services NICE guideline CG138 (2012)

Autism spectrum disorder in adults: diagnosis and management NICE guideline CG142 (2012)

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges NICE guideline NG11 (2015)

Home care: delivering personal care and practical support to older people living in their own homes NICE guideline NG21 (2015)

Older people with social care needs and multiple long-term conditions NICE guideline NG22 (2015)

Transition between inpatient hospital settings and community or care home settings for adults with social care needs NICE guideline NG27 (2015)

Older people - independence and mental wellbeing NICE guideline NG32 (2015)

Transition between inpatient mental health settings and community or care home settings NICE guideline NG53 (2016)

Mental health problems in people with learning disabilities: prevention, assessment and management NICE guideline NG54 (2016)

People's experience in adult social care services: improving the experience of care for people using adult social care services NICE guideline. Publication expected February 2018

Learning disabilities and behaviour that challenges: service guidance NICE guideline. Publication expected March 2018

7 Contributors and declarations of interests

Members of the Committee and other contributors to the guideline declared any relevant interests. [Add guideline number to hyperlink] in line with the conflicts of interest policy.

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	including older people and their family carers (Recruitment)	financial (non-specific)	
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	Interest Group at Royal College General Practitioners		the matter under discussion
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Jill Rasmussen	Director and Co-founder of psi-napse. psi-napse is an independent consultancy specialising in advising about psychiatry and neurology research; CNS strategic drug development, medico marketing and education; venture capital providers about potential investments in the CNS sector.	Personal financial (specific)	Reviewed in light of discussion around some of the recommendations but no action was needed
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Laurence Taggart	Co-authored the following papers that were reviewed as part of the evidence-base: McIlfatrick, S. J., Taggart, L. & Truesdale-Kennedy, M. N. (2011): Supporting women with intellectual disabilities to access breast cancer screening: a health care professional perspective. European Journal of Cancer Care, 20,412 – 420. Truesdale-Kennedy, M. N., Taggart, L. & McIlfatrick, S. J. (2011): Breast cancer knowledge among women with intellectual disabilities and their experiences of breast mammography. Journal of Advanced Nursing, 67 (6), 1294 – 1304.	Personal non-financial (specific)	Declared and did not participate in group discussion on specific evidence statements related to these studies. The group work to review the evidence and write recommendations was organised accordingly.

	Taggart, L., Truesdale-Kennedy, M., Ryan, A. & McConkey, R. (2012): Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. Journal of Intellectual Disabilities, 16 (3), 217-234. Ryan, A., Taggart, L. & Truesdale-Kennedy, M. (2014): Issues in caregiving for older people with intellectual disabilities and their ageing family carers: a review and commentary. The International Journal of Older People Nursing, 9 (3). pp. 217-226. Taggart, L. & Cousins, W. (Eds) (2014): Health Promotion for People with Intellectual Disabilities. Open University Press/McGraw-Hill Publishers: Maidenhead, England. ISBN: 9780335246946. McConkey, T., Taggart, L. & Kane, M (2015): Optimising the uptake of health checks for people with intellectual disabilities. Journal of Intellectual Disabilities, 19(3), 205-214.		
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8 Glossary and abbreviations

Glossary

Advocacy and advocates

Help to enable people to get the care and support they need that is independent of services. An advocate helps people express their needs and wishes, and weigh up and take decisions about the options available to them. They can help people find services, make sure correct procedures are followed and challenge decisions made by councils or other organisations.

Person centred care

An approach that puts the person receiving care and support at the centre of the way care is planned and delivered. It is based around the person and their needs, preferences and priorities.

Reasonable adjustments

Changes that public services, buildings and employers have to make to make it possible for people with disabilities to use a service or do a job.

Residential care

Care in a care home, with or without nursing. Care homes offer trained staff and an adapted environment suitable for the needs of people who are ill, disabled or have a learning disability.

Supported living

An alternative to residential care or living with family that enables adults with disabilities to live in their own home, with the help they need to be independent. It allows people to choose where they want to live, who they want to live with, how they want to be supported, and what happens in their home.

Please see the NICE glossary for an explanation of terms not described above.

Abbreviations

Abbreviation	Term
AD	Alzheimer's disease
ADRC	Aging and Disability Resource Centers
BILD	British Institute of Learning Disabilities
BMI	Body Mass Index
CLDTs	Community Learning Disability Teams
DD	Developmental Disabilities
EPPI	The Evidence for Policy and Practice Information and Co-ordinating Centre
F/f	F-test; F-statistics
GBP	Great British Pound
GC	Guideline Committee
GDS	Glasgow Depression Scale
GP	General practitioner
ICER	Incremental Cost-Effectiveness Ratios

ID	Intellectual disability
I/DD	Intellectual and developmental disabilities
IDS-TILDA	The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing
IPA	Interpretative phenomenological analysis
LD	Learning disability
LTSS	Long term support and services
MWLQ	Modified Worker Loneliness Questionnaire
NHP	Nottingham Health Profile
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OECD	Organisation for Economic Co-operation and Development
OPLD	Older people with learning Disabilities
p	p value (statistical significance)
PA	Physical activity
PAS-ADD	Psychiatric Assessment Schedules for Adults with Developmental Disabilities Checklist
PEG	Percutaneous endoscopic gastrostomy
PICO	Population, intervention, comparison; outcome,
QALYs	Quality-adjusted life years
RCT	Randomized controlled trial
SD	Standard deviation
T/t	Student's t test
TTR	Transition to retirement
UCLA	University of California, Los Angeles
UK	United Kingdom
USA/US	United States of America
VEC	Vocational Education Committee

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 care and support of older people with learning disabilities (see the scope). [update hyperlink with guideline number]

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

For consultation document: We will develop a pathway and information for the public and tools to help organisations put this guideline into practice. Details will be available on our website after the guideline has been issued.

For final document: 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 [update hyperlink when guideline number is assigned].

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