

Challenging Behaviour in Learning Disabilities **Stakeholder Workshop, 1-4pm 18 April 2013**

Group 1

Scope

4.1 Population

4.1.1 b) the group felt that 'offending behaviour' was a more appropriate phrase for this section.

4.3 Key Issues

- 4.3.1 c) the group felt this section should be reorganised to list all the interventions under one section and that the list of psychological/psychosocial interventions should be expanded.
- Transition between services needs to be added to this section
- Support for employers and employees should be added to this section
- People need to be supported to access housing

4.4 Outcomes

The group suggested the following additional outcomes:

- Premature death
- Reduction in health inequalities
- Improvement in physical health
- Employment rates
- Reduction in inpatient admissions
- Length of stay in inpatients
- Out of area placements

Inequalities

- Young men may have a greater risk of being restrained.
- Those with profound disabilities, particularly individuals who are non-verbal.

Additional considerations

- The group felt that the term 'challenging behaviour' would lead to this being seen as a diagnosis, rather than a behaviour that comes and goes, and that can often be prevented. The phrase 'behaviour that challenges' should be used instead.
- The differences between severity of the learning disability should not be highlighted as this leads to greater divisions in services.
- Early intervention is important to prevent challenging behaviour.
- Prevention – Greater support is needed to prevent both development of challenging behaviour and the continuation of it.
- Positive support for workforce skills/training should be encouraged.
- Social care and education need to be included.
- The individual needs of a person should be assessed, rather than just their healthcare needs.
- There needs to be a greater emphasis on integrating people into the wider population rather than focussing on specialist services.

GDG constituency

The group suggested GDG members in addition to those suggested by NICE:

- Occupational health therapist
- Psychotherapist
- Employment advisors/support workers
- Commissioners
- Training agencies

The group suggested that a reference or focus group be used to gain the input of service users.

Group 2

Scope

4.1 Population

- 4.1.1 a) Guideline must consider age range where most problematic – half of people with Learning Disability are outside of prescribed area
- 4.1.1 a) Group pleased by breadth of scope as space to include children and young people
- 4.1.1 b) Needs greater emphasis on preventing the need for Criminal Justice System intervention
- 4.1.1 b) Concern that people with Learning Disability are under diagnosed by the Criminal Justice System
- 4.1.1 d) Group suggests Learning Disability be termed Intellectual Disability

4.3 Key Issues

- 4.3.1 a) Greater emphasis needed on prevention
- 4.3.1 b) Physical health needs greater emphasis, investigation of co-morbidities
- 4.3.1 b) Health concerns: Epilepsy, Autism, Dementia
- 4.3.1 b) Health services for Epilepsy are poor, often paediatric neurologists but no adult neurologists
- 4.3.1 b) co-ordination of care essential
- 4.3.1 c) social interventions should be included
- 4.3.1 c) Sensory therapies, social interventions and alternative interventions should be distinct categories
- 4.3.1 d) the group raised concerns with use of Anti-psychotics
- 4.3.1 d) the group raised concerns with management of long term medication
- 4.3.1 e) Physical and mechanical restraint should be two distinct categories
- 4.3.1 e) the group raised concerns about restraint training/education - SCIPr, RESPECT training
- 4.3.1 h) Interventions for families and carers crucial
- 4.3.1 h) Poor physical health of parents an important concern – respite
- 4.3.1 h) Aging of carers important

Key Outcomes:

- Developmental profiles
- Admission to care – recording rates used to inform GDG
- Research on case series
- Environmental issues. E.g. Clinical supervision shortages
- FRITH prescription guidelines

GDG Constituency:

The group suggested GDG members in addition to those suggested by NICE:

- Neurologists
- CJS /Forensics
- Inpatients/ family carers
- Occupational therapists
- Nurses (especially for children and young people)
- One non-NHS provider
- Non-profits

Group 3

Scope

4.1 Population

- It is important that the issues of those with mild learning disabilities are addressed.
- 4.1.1 Those being treated under the mental health act need to be addressed. A number of factors to be considered: deprivation of liberties (DOLs), issues of capacity and consent (including families and carers as they can support capacity/consent/shared decision making), mental health act status, safe-guarding.
- 4.1.1 b) “Those within the criminal justice system” – it should be clearly defined who this applies to.

4.3 Key Issues

- 4.3.1 c) It needs to be clear that not only behavioural or cognitive-behavioural interventions are being considered – examples of other therapies should be given.
- Sensory sensitivities/sensory processing problems should be added to this section
- Appropriate interventions for different ages need to be considered
- There needs to be a greater emphasis on prevention
- 4.3.1. a) and h) greater clarity is needed in these sections
- Need to add sexual development education here

Inequalities

- Consideration of those from minority groups accessing services
- Accessibility for those who lack the language skills to convey their needs (both service users who have low verbal ability, but also service users/families who have difficulty with English).
- Socioeconomic concerns – e.g. families missing out on early intervention due to lack of funds/funding support

Additional considerations

- The group felt that the title does not suggest a proactive prevention approach and should be amended to: “treatment, support and management of challenging behaviours in people with learning disabilities”
- Inclusion of social care needed as much of the support offered to those with LD is in a social care context.
- Focus on safe services – number of staff, expertise and training of staff needs to be considered.
- Safeguarding procedures and how this links into physical interventions/seclusion need to be considered.

GDG constituency

The group suggested GDG members in addition to those suggested by NICE:

- Occupational therapy (sensory issues, environmental issues, supporting care staff)
- Someone who specialises in behaviour analysis (linked to below)
- A representative whose specialism is non-verbal communication (body, behaviour, movement, intensive interaction, sensory support).
- Someone from supported employment.
- A representative who is involved in the training and education of physical interventions
- A representative who has experience of positive behaviour support
- A learning disability nurse (physical issues, pain) for both adults and children
- Someone from education (SENCO or special education specialist)
- Representatives from known support/action groups (NDTi [National Development Team for Inclusion] and Children and Young People’s Service)
- Representatives from both statutory and non-statutory services
- Representation for particular groups of services e.g. offenders. It would be useful to have offender managers who are used to applying interventions. ‘Working for Justice’ is a group for people with LD within the criminal justice system.

- Representative from a residential school
- Health visitors/early intervention specialists and others who may need additional training and support in their role

Service user and carer representation

Families on behalf of those who are non-verbal

It may be necessary to have external organisations/reference groups to represent service users.

Established groups that can provide support e.g. 'Shaping Our Lives' for people with LD).

Group 4

Scope

4.1 Population

- These people seem to be functioning reasonably well so they are overlooked by services.. They fall into gaps because their problem is not severe but they nonetheless have needs and these are not being met
- There are also a group of people with no diagnosed learning disabilities needing help (borderline mild). They need emotional support/help with problem solving.
- This is a vulnerable group they are a risk to themselves and others (potential to harm themselves/people/property).
- There are 3 main categories of people with LD needing support:
 - Children developing behavioural problems
 - Adults not getting needs met who then become difficult to support
 - People with challenging behaviour who are known to services.

4.3 Key Issues

- There needs to be greater emphasis on anticipation and prevention needs.
- the terminology in this section should be amended - not "in" individuals with LD.
- Include sensory processing disorders as well as physical health
- The interventions should include:
 - Personal planning
 - Active support
 - Give them communication skills
 - Attachment focus
- b) Add physiological assessment after physical health
- g) Holistic support needed

Additional considerations

- The title should be amended to: Challenging behaviour – understanding and supporting people with challenging behaviour and learning disabilities
- Greater attention needs to be given to families who are flagging problems before the situation becomes critical but this is not picked up and dealt with. The focus of the guideline needs to be on 'prevention' rather than cure:
 - Identifying vulnerability before behaviour becomes challenging
 - Group with very severe learning disabilities who need attention.
- People are referred to assessment and treatment units when their behaviour has become a serious problem but practice varies across units.
- People are seen as the problem, rather than the environment and a failure of services to respond.
- Support is needed in education.
- There are a number of Interfaces that the guideline will have to deal with: social care and health care/privately funded/ supported living
- An important question for the guideline to consider is how to help families in crisis. Support is needed in home e.g. respite care
- The coordination of care needs to be addressed.
- The workforce in many care providers is unskilled/temporary/high turnover. NHS services are asked to give repeat training.
- Training needs to be embedded in services

- Basic training is needed and then additional training can be provided for more complex/bespoke training
- Core competencies need to be established for people working in that field

GDG constituency

The group suggested GDG members in addition to those suggested by NICE:

- Occupation therapy
- Family – adult and child (experience of carer)
- Carers/carer group
- Family therapist specialising in LD
- Behavioural analyst
- Front line staff supporting people
 - Social care
 - Health care
- Community nurse with a specialist interest
- Commissioner