

## Learning Disabilities and Mental Health Problems – Stakeholder Meeting

10am-1pm, 27 May 2014

### Group 1

1. *Scope - Are we on the right track? Have we struck an appropriate balance between the need to keep the scope manageable and covering the most important clinical issues?*

#### Introductory material

- Title - 'problem' will be misinterpreted by social care practitioners
- Issue with the wording of "problems" – suggesting using "needs" instead. "Management" = 'to do to' rather than 'to do with' - suggested changing to "prevention and management" or 'Needs' instead?
- Need to cover problems and needs in the early years/from birth (this is picked up in section)
- Also, from a SC point of view, 'management' suggests 'doing something to' the person with LDs
- 'Meeting the mental health and emotional needs of people with LDs?' as a new title
- Section 3 light on early years, where prevention is key.
- Consider adding something on protective factors as well as risk factors.
- Issues for early years:
  - Teaching to communicate
  - Family
  - Transition from primary to secondary education (specific regulations around this transition)
- Other issues:
  - Lack of access to services (mild; present in a similar way to those without learning difficulties, adjustments to care not being made or taking longer)
  - Age based transitions often around commissioning/ can be very variable
  - Link to CBLD guideline □ "at risk of developing" missed otherwise same group (the group believed the evidence for this guideline will be a mild-moderate group).
  - Self-funding to be included (particular relevance to older people)

#### Population

- add people at risk (links to prevention)

#### Settings

- Sfc - what about people who are self-funded, particular relevance to older people
- Include criminal justice settings
- Add 'including their family home'?

- Add educational settings (Sometimes only way to access people)
- Care setting (noted a possible cross reference to this guideline from the prison guideline)
- Helpful to include secure forensic hospital services
- “resides” needs to be removed as it excludes groups, add “including their family home”
- Important to add educational settings (exclusion happens because of behaviour)
- Suggested using evidence base from healthcare professionals who work in schools already

## Outcomes

- Medical model too prominent
- Multi-faceted approach needed
- Self-reported outcomes
- Observation
- Awareness of own MH
- How patient feels and coping strategies

### 2. *Should the criminal justice system be included under settings (4.2)?*

- Yes, need to include forensic settings.

### 3. *Do the topics listed in the scope (section 4.3.1) cover the most important areas? Are there any omissions or any topics on the list that should be deleted?*

- Communication support for people with LDs
- needs to be explicitly mentioned in b) and c)
- Commissioning interventions/service delivery?
- Changing the package of care can change outcomes
- (There is evidence but it's unpublished)
- Co-design etc. with family carers and paid carers?
- In CBLD scope but not in this one
- (King's Fund looking at co-design)
- Art therapy (e.g music therapy)
- interventions to promote mental well-being?

### 4. *Equalities – how do inequalities impact on the provision of care for people with challenging behaviour in people with learning disabilities? Should any particular subgroups of the population be considered within the guideline?*

- The group did not identify any equality issues

### 5. *Regarding the suggested guideline development group composition – are all the suggested members appropriate? Should we be including any other types of members for this guideline? Could there be a role for expert advisers in this guideline?*

- Educational psychologist
- Special education needs coordinator
- MH nurse
- Psychological therapist

## Group 2

1. *Scope - Are we on the right track? Have we struck an appropriate balance between the need to keep the scope manageable and covering the most important clinical issues?*
  - The group agreed that the scope covers the most important issues, although it is a rather ambitious scope.
  - People with learning disabilities and mental health problems are often treated in general mental health services where there is not the expertise to treat them. This can lead to their needs not being met, as well as safeguarding issues.
  - It is imperative that the guideline covers the full range of severity of learning disabilities.
  - The group discussed the use of IQ scores in relation to identifying the needs of the individual. It was agreed that it is not helpful for children who need to be looked at in terms of functionality, however it is often used when assessing those in forensic settings.
  - It was agreed that it is very important that the guideline makes recommendations about the recognition of mental health problems in those with learning disabilities. This is particularly a problem in forensic settings.
  - There can be issues in primary care with identify mental health problems in those with learning disabilities. This is greater in adults as GPs are often the only contact individuals have with the health service.
  - The interface between education and health care is very important for how well children and young people are identified and supported.
  - Sexual offending behaviour and sexual exploitation/abuse needs to be covered in the scope.
2. *Should the criminal justice system be included under settings (4.2)?*
  - Yes, need to include forensic settings. This is a very expensive and problematic issue, particularly in relation to inappropriate/offending sexual behaviour.
3. *Do the topics listed in the scope (section 4.3.1) cover the most important areas? Are there any omissions or any topics on the list that should be deleted?*
  - The group agreed that all relevant interventions are covered.
4. *Equalities – how do inequalities impact on the provision of care for people with challenging behaviour in people with learning disabilities? Should any particular subgroups of the population be considered within the guideline?*
  - Adolescents – there is a large inequality between child and adult services and the transition between these services in adolescence often results in people being let

down by services. It can be a complicated process, particularly as health and social care criteria for services are different.

- There is a potential problem for the transition to older adults' services as the aging population increases.
- It is difficult for minority ethnic groups to engage with services and for services to meet their needs. This can be a particular problem for people from eastern European countries.

5. *Regarding the suggested guideline development group composition – are all the suggested members appropriate? Should we be including any other types of members for this guideline? Could there be a role for expert advisers in this guideline?*

- Need to specify a social worker and a social care residential provider.
- Teachers of children with learning disabilities
- Special educational needs coordinator (SENCO)

6. *Other considerations raised by the stakeholders:*

- The Biological Association of Psychiatrists have recently published an evidence based guideline in this area – may be able to share some reviews.
- The Children's and Families Act aimed at improving joined up working and ensuring services work together more effectively will come into force in September 2014. This includes new rules around commissioning services for children and young people up to 25 which should help with the access and provision of services. It also includes youth offending.

### **Group 3**

1. *Scope - Are we on the right track? Have we struck an appropriate balance between the need to keep the scope manageable and covering the most important clinical issues?*

### **General points**

- Need to clarify where care occurs
- Need to add education (e.g. schools, colleges, residential schools) and the criminal justice system to MH and LD services
- Inclusion criteria should be more about patient needs and based on a clinical assessment rather than an IQ score (group noted that for research purposes this may not be practical, but should be considered in recommendations). For example, a person with a neurodevelopmental disorder with an IQ above 70 would need different mental health care than the general population.

### **Section 4.1.1**

- Autism, ADHD and co-morbidities need to be covered with reference to other guidelines
- Some neurodevelopmental disorders will not be picked up – it is important not to depend only on IQ as a diagnosis.

#### **Section 4.3 D)**

- Children with MH difficulties need to be able to access appropriate services
  - Psychological interventions need to be accessible
  - More appropriate support tailored to people with learning difficulties is needed
2. *Should the criminal justice system be included under settings (4.2)?*
- It was agreed it should.
3. *Do the topics listed in the scope (section 4.3.1) cover the most important areas? Are there any omissions or any topics on the list that should be deleted?*

#### **4.3.1 B)**

- Need to assess tools for recognition, assessment and risk assessment

#### **4.3.1 C)**

- Should consider pharmacology for mental ill health (due to presence of other conditions, polypharmacy etc.)
- Could consider complementary therapies? (e.g. herbal, massage, aromatherapy etc.)
- Should include combined and multidisciplinary approaches
- For the prevention interventions it would be good to look at health checks, social care and social determinants of mental ill health

#### **4.3.1 E)**

- Include county areas and residential schools
4. *Equalities – how do inequalities impact on the provision of care for people with challenging behaviour in people with learning disabilities? Should any particular subgroups of the population be considered within the guideline?*
- Standard protection groups
  - Types of accommodation/support
5. *Regarding the suggested guideline development group composition – are all the suggested members appropriate? Should we be including any other types of members for this guideline? Could there be a role for expert advisers in this guideline?*
- Psychiatrists/psychologists from both LD and mainstream services
  - Child and adult specialists
  - Pharmacy?
  - Forensic mental health services
  - Allied health professionals or other allied professionals (e.g. physiotherapists, occupational therapists)
  - Umbrella organisations for provision of care

## Group 4

1. *Scope - Are we on the right track? Have we struck an appropriate balance between the need to keep the scope manageable and covering the most important clinical issues?*

Generally the scope was considered to be on the right track, however:

### General comments

- The group felt that the role and impact of education services should be made more explicit in the scope
- Important to consider the interplay between diagnoses in those with complex comorbidities (e.g. learning disability + autism + other mental health diagnosis)
- When discussing 4.2 'care settings' the group thought it was appropriate to specify that this could include the service user's own home and the care arrangements therein, as well as formal residential placements.
- The group considered the wording of section 3.1, paragraph (g) to be quite broad as it mentions a wide range of underlying factors that may contribute to mental health problems. The breadth of this point is further increased when we consider the role that each underlying factor plays within subgroups of individuals with learning disabilities (e.g. moderate, mild, severe). It was deemed that some of the underlying factors, such as poverty, may be considered when the guideline looks at specific interventions such as social interventions, thus making the broad category of 'underlying factors' more manageable. Although, overall the group stated that it may be beneficial to take such a broad approach to the exploration of factors that contribute to mental health, particularly in areas where evidence is expected to be limited.

### 4.4 Main Outcomes

- Under 4.4 'main outcomes' the group felt that section (a) 'Mental health and problem behaviours' should be reworded as they stated that 'problem behaviours' could be considered a vague and negative term. The group further stated that the items 'mental health' and 'behaviour problems' should be separated and considered as different topics.
- The group stated that the wording of outcomes, and of the scope in general, should be more person-centred. For example, in section (g) 'Adverse effects of interventions' the group raised the question 'for whom are the effects adverse?'; for example, sedation as a side effect of medication could be perceived as beneficial from the perspective of some carers if it reduces challenging behaviour, but it may be experienced as aversive to the service user.
- For section (h) 'Rates of placement breakdown', the group stressed that the wording of this item was, again, quite negative. The group stated that this topic should take into account the extent to which services are suited to an individual's needs and that appropriate placement relies on appropriate assessment. The group felt that the guideline should take into account a 'least restrictive/optimal placement approach when developing the guideline.
- Overall, the group expressed that outcomes should be more clearly oriented towards a strength based recovery model of mental health that considers a service user's skills and positive attributes, rather than the deficit based medical model that is implied by the current wording of the scope.
- The group considered (j) 'Out-of-area placements' to be an important topic and stated that it is important to consider the reasons for placement (such as

- improved access to specialists, separation for antisocial peers, or resource limitations).
- The group felt that one omission in the outcomes may be the consideration of skills-based outcomes, such as access to employment.
2. *Should the criminal justice system be included under settings (4.2)?*
- The group said that discussion of the criminal justice system may be especially useful at the custody diversion stage, adding that teams have been established to direct individuals with learning disabilities and mental health needs to care services, rather than prison.
3. *Do the topics listed in the scope (section 4.3.1) cover the most important areas? Are there any omissions or any topics on the list that should be deleted?*
- In section 4.3.1, paragraph the group wanted further clarification of section (d) 'accessibility of services'. The group stated that this section could cover a diverse range of topics, such as service users' proximity to services, the logistics of travelling to services and how individuals are initially referred to services. The group also felt that this should allow discussion of the effectiveness of adapted interventions, but also the appropriateness of mainstream interventions to which 'reasonable adjustments' have been made to suit the needs of service users. The group stressed that individuals with learning disabilities may often be wrongfully excluded from effective interventions for mental health that are used within the general population, as it is assumed that individuals with learning disabilities will not be able to engage appropriately with these interventions.
  - For section (c) 'social interventions', the group wanted further clarification on what is meant by the heading and queried whether it would include things like employment, public health interventions and purposeful activity.
  - Section (e) transitions between services was considered especially important and the group stated that this topic should include components of effective transition planning. Transitions from health to social care, child to adult services, and from primary to secondary school were highlighted as key transition stages for individuals with learning disabilities and mental health needs.
  - Under section (a) 'recognition of mental health problems', the group stated that it is important to consider factors that may contribute to mental health problems, such as adverse environments. As the challenging behaviour and learning disability guideline looks at environmental interventions it may be worthwhile considering this type of intervention in the learning disabilities and mental health guideline.
4. *Equalities – how do inequalities impact on the provision of care for people with challenging behaviour in people with learning disabilities? Should any particular subgroups of the population be considered within the guideline?*
- The group felt that the wording 'a number of equality issues' was vague and should be made more specific in the scope.
  - The group identified subgroups of individuals for whom special consideration is warranted within the guideline as being: Those with sensory impairments and communication needs (such as individuals with non-verbal communication); ethnic minorities; those living in rural vs central locations (as this may impact on access to services); age subgroups and gender subgroups.

- The group felt that it was important to consider the role of service users' capacity in terms of their ability to have a 'voice' or to consider input from families when capacity is lacking and to tailor recommendations accordingly.
5. *Regarding the suggested guideline development group composition – are all the suggested members appropriate? Should we be including any other types of members for this guideline? Could there be a role for expert advisers in this guideline?*
- More than one type of social care professional should be included on the guideline and the need for specific types of professionals should be made clear when advertising for group members (e.g. GPs, inpatient care staff, outpatient care staff).
  - There should be an equal representation of individuals who work with adults and children
  - It was felt important to include people with experience within educational services – both state and residential.
  - Public Health England have a mental health branch and this may be useful for identifying a group member with useful public health knowledge.
  - Possibly include Improving Access to Psychological Therapies (IAPT) practitioners
  - Include individuals from *Child and Adolescent Mental Health Services (CAMHS)*
  - People with experience in forensic settings
6. *Other considerations raised by the stakeholders:*
- The *Children and Families Bill* (<http://services.parliament.uk/bills/2012-13/childrenandfamilies.html> ) should be considered as context for the guideline, as should The Quality Standards for Health and Social Care.