

# NICE Collaborating Centre for Social Care

## Older People with Learning Disabilities guideline

15/07/15

### Stakeholder Scoping Workshop Notes

#### Break-out group discussions

Four facilitated break-out groups discussed specific aspects of the draft scope. This paper summarises the themes that emerged.

#### Priorities for the guidance

The groups discussed the most important issues the guidance should tackle. These are summarised below.

#### Specific comments on the scope document

##### Are the right population groups identified and included?

Overall the four groups were in agreement that the scope should:

- Include people not known to services and
- NOT specify an age threshold

Despite agreement from all groups that it would not be beneficial to specify an age threshold, concerns were raised that the standard retirement age (65+) would be applied inappropriately to this population on account of the word 'older'. Two of the groups voiced preference for the word 'ageing' rather than 'older'. Partly, stakeholders felt this word was better suited to capture the changes that occur because of the ageing process. In addition it was felt that describing the population as 'people with learning disabilities *who are ageing*' would help to emphasise the specific age related difficulties (early onset dementia, prevalence of chronic diseases) which tend to affect this group at an earlier age than the rest of the population. Stakeholders from each group expressed that the guideline was likely to be relevant to people with learning disabilities starting from the age bracket of 40+ or 50+, rather than 60+.

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Some stakeholders suggested that the scope should include definitions of ‘family’, ‘carer’ and ‘family carers’ in addition to adapting the population of the scope to include carers.

### **Are the definitions about the population appropriate/ workable?**

All groups felt it was appropriate to use the definition of ‘learning disability’ found in [Valuing People](#) (Department of Health, 2001).

However, one group felt that it would be useful to include an additional line from the definition which explained the complexity and range of the spectrum of disabilities. Another group pointed out that the ‘Valuing People’ definition was not appropriate for people on the autistic spectrum. By this definition people with Asperger’s would be included, but the group questioned whether their inclusion was appropriate.

### **Are there any equalities issues that we should be considering?**

Equality issues around BME and LGBT groups were referenced, especially in relation to how their support networks are more likely to be outside mainstream learning disabilities services, and may be more in line with their cultural or sexual identities. Many stakeholders recognised the specific equalities issues in question but did not feel it was appropriate to highlight any one group with protected characteristics above any other.

### **Are the audiences described appropriately?**

Stakeholders suggested the following additions to the audiences which the scope is relevant to:

- Health and Wellbeing Boards
- Safeguarding boards
- Main stream services – as well as specialist
- Practitioners working in palliative care
- Advocates in audience
- People working in the criminal justice system
- Care Quality Commission (CQC)

## **Settings**

### **Are the right settings included?**

Stakeholders felt that the settings did not adequately reflect the range of diversity in people with learning disabilities’ living situations; the scope should address the whole range of levels of (in)dependence and caring relationships that exist within this population.

All groups suggested that prisons and criminal justice settings should be added.

Other common suggestions were: family (parental) homes; specialist learning disability inpatient services; rehabilitation clinics; community pharmacies, opticians and other high street settings; respite care settings (to differentiate from temporary accommodation as a homeless shelter).

One stakeholder commented that the use of ‘warden-supported accommodation’ should be avoided because of its institutional connotations, suggesting instead ‘housing scheme manager’.

Another stakeholder commented that it was not possible to create an exhaustive list of all relevant settings, especially when considering that some people with learning

disabilities are not known to services. Mirroring this concern other individual stakeholders felt a list of individual settings was inappropriate because they felt strongly that ALL settings were relevant, wherever the person with learning disabilities may be.

### **Are the right activities and interventions included?**

#### Identification and assessment of health and social care needs in older people with learning disabilities

Three groups felt that assessment of caregivers' needs should be added to the first key area.

#### Information, advice, training and support for older people with learning disabilities and their families and carers

One stakeholder group felt strongly that 'information, advice, training and support' (which was point 5 under key activities) should be moved up the list as it was integral to all other activities. Across other groups it was also felt that the wording of this activity should be made less passive; the consensus was that this activity should emphasise how people with learning disabilities can be enabled to exercise choice and control. Stakeholders also commented on the need for accessible information in easy-read formats (e.g. bus timetables and not just health appointments).

#### Interventions to support access to health and social care services, including screening, health checks and advocacy (including self-advocacy).

One group felt that advocacy/ advocates would be better placed in point 5 (Information, advice, training...). Stakeholders felt that 'access to mainstream services, including reasonable adjustments to mainstream services' should be added to this point (or reflected in the list of interventions).

#### Care and support planning, risk management and review for older people with learning disabilities, including joint working with housing, employment, education and related services.

One group felt that 'review' risked being lost in this point and that a separate bullet should talk about contingency/early/forward planning for older age. Other groups echoed this sentiment by referring to the need for planning for age-related transitions, such as the move from community to assisted living.

Similarly a lot of groups discussed the need to cover preventative measures and early interventions, for example health promotion initiatives to help people with learning disabilities maintain healthy lifestyle choices. (This could be addressed in this point or in the list of interventions below).

#### Interventions and elements of care and support for older people with learning disabilities, including the provision of:

- *Support to self-manage health conditions*

Most groups felt that this activity should be expanded, and should incorporate preventative measures and healthy lifestyle initiatives.

- *Practical and emotional support (relating to finances, retirement, bereavement and life changes)*

Stakeholders felt 'well being' should be added and emphasised in this point. There are so many challenges for this population; stakeholders wanted to highlight the steps which could be taken to empower and help people with learning disabilities to retain a sense of identity and forge and maintain meaningful relationships. A few stakeholders also referred to the value of peer support as a tool for improving quality of life.

- *Support to reduce social isolation including through volunteering, social and leisure activities and transport*

Two groups felt that 'reduce' was a negative word, and should be replaced by 'develop and maintain relationships'. The addition of 'technology' (i.e. apps and tech innovations to maintain social networks) was suggested.

Stakeholders commented that re-housing can have negative effects on valued community networks.

- *Care and support at the end of life*

Access to palliative care was felt to be an important issue. One stakeholder suggested that 'Palliative Care for People with Learning Disabilities Network' should be approached as a stakeholder group. Another stakeholder suggested looking at the CIPOLD report for this area.

- *Training of social care staff to identify and manage common health conditions in older people with learning disabilities*

Two groups felt that training should be around personalisation. Stakeholders also suggested that training should not just be limited to social care staff, but would be relevant to health care and even police staff. (Although NICE's remit would only allow us to address the interface of these services).

### **Do they cover all the aspects of care and support for older people with learning disabilities?**

Peer support and befriending schemes were suggested by a few stakeholders. Telecare and assistive technology were suggested as additional interventions.

### **Are any of them unnecessary/ inappropriate?**

Safeguarding was felt to be 'no more applicable' because of the ageing process. Some suggestions were made to merge point 2 and 5. Another group felt that point 3 'Care and support planning, risk management and review' was disposable as it would be covered by the other activities.

### **Are the excluded activities appropriate and workable?**

Stakeholders seemed to agree with the excluded activities.

### **Will the review questions allow us to address the most important issues?**

Three groups queried why safeguarding was first on the list of review questions. It was felt that this issue was not particularly relevant to this population. Aside from underpinning the Mental Capacity Act there was unlikely to be a lot of evidence on this topic and inter-agency working was suggested as a more useful topic to focus on.

Stakeholders suggested that the key activities should be used as a frame to structure the review questions around.

RQ2) What is the effectiveness and cost effectiveness of supported living for older people with learning disabilities?

Two groups suggested changing the second question about 'support living' to cover all housing.

RQ3) What are the views and experiences of older people with learning disabilities and their carers about care and support in inpatient hospital settings?

Similarly, one stakeholder group suggested that 'inpatient hospital settings' should be widened to cover all health settings (community, inpatient, acute etc.).

**Are there any other review questions we could consider (within scope)?**

The following additional review questions were suggested:

- A question around health-related prevention and access to appropriate health checks and information provisions. (Four elements that affect success: service, transport, support and information).
- A question comparing mainstream versus tailored services. (This was suggested as the review questions seem to assume that services are all tailored to learning disabilities, but mainstream services can sometimes be adequate for certain things).
- A question on transitions between settings for people getting older. (Consideration could be given to planning and information and training for staff).

**Outcomes**

At least two of the groups commented on the importance of the 'continuity of care' outcome. However, stakeholders sought clarification over whether this simply meant having the same carer or if pertained to joint working protocols with a person-centred focus and outcomes relating to re-housing.

Suggestions were made to add the following outcomes:

- Respect and dignity
- Participation in everyday life/ chosen activities
- Cultural sensitivity
- Identification
- Commissioning outcomes
- Exclusion from care homes (as well as admission)
- Premature deaths
- Quality of life outcomes should also include independence, choice and control
- Healthy life years (as important as years saved)
- Confidence about the future – security and sustainability

**Guideline Committee (GC)**

One group suggested seeking nominations from the learning disabilities professional senate. Stakeholders suggested the following representatives for the guideline committee:

- Commissioners (CCG & LA)
- General nursing home
- General practitioner
- Learning disability nurse
- Provider representatives (including mixture of residential care, supported living, day services, mainstream services for older people)
- Social Worker
- Social Care provider
- Someone with inpatient background
- Service users and carers
- Academic - someone with good theoretical knowledge
- Someone who knows how things work in different places, national understanding consultancy styles
- Housing policy/association background
- Training/workshop development
- Equality and diversity expertise
- Someone from a health and well being board
- Voluntary carer and advocate groups

### **General comments on scope and hopes for guideline**

Certain stakeholders felt that guideline should highlight the responsibilities of local authorities and health and well being boards. Others felt that the key issue was support for people with learning disabilities to access mainstream services. The diversity and heterogeneity of the population was a recurring consideration in the stakeholder comments, as was the importance of 'well-being', i.e. support to enable people with learning disabilities to lead an ordinary life by taking a holistic approach which looked beyond just health care settings.