

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE guidelines

Equality impact assessment

Care and support of older people with learning disabilities

The impact on equality has been assessed during guidance development according to the principles of the NICE equality policy.

1.0 Scope: before consultation (To be completed by the developer and submitted with the draft scope for consultation)

1.1 Have any potential equality issues been identified during the development of the draft scope, before consultation, and, if so, what are they?

The following equality issues were identified during the development of the scope by the NCCSC and at the stakeholder workshop, and agreed by the scoping group.

People who are not known to care services: “Up to 25% of people with learning disabilities living with older family carers, are not known to services until there is a crisis” (Department of Health, 2001, quoted by the [British Institute of Learning Disabilities](#)). Not being identified as having learning disabilities may reinforce inequity of access to appropriate care and support – including additional health surveillance and preventative care.

LGBT people: This is possibly the first generation of older people to be active in seeking services appropriate for LGBT people. Services may, for example, fail to recognise the role of same sex partners identified by the person as such.

People of minority ethnic background: Research suggests that minority status in cultural, religious and language characteristics among some people from black and minority groups disadvantages them in accessing social and health care and support. Within this population, disadvantage will be exacerbated by having a

learning disability. Services should be sensitive and responsive to different cultural and religious requirements and the difficulties in accessing services that these groups may face. Recent migrants, including refugees and asylum seekers, and people who do not speak English as their first language are likely to have reduced knowledge of, and hence access to, social care services.

Gender, sexual health and ageing: There are issues for both sexes receiving personal care concerning the sex of the worker – can health and social care services accommodate preferences?

People with learning disabilities may have less knowledge of or insight into the gender-based aspects of ageing, such as the menopause (for women), and the need for prostate surveillance in men. People may also need guidance on sexual health and safety, and on public health screening programmes.

There are issues around equality and discrimination applied to older people in general which will have an impact on this group.

People with co-morbidities: Certain conditions such as cerebral palsy, autism and epilepsy, are associated with learning disability because people with these conditions are more likely to have a learning disability. “All people with learning disabilities are at greater risk of developing dementia than the general population (22% vs 6% aged 65 and above) ([British Institute of Learning Disabilities](#)). People with learning disabilities are also more likely to develop other conditions common in older age – such as osteoporosis and diabetes – when they are younger, and services to address these conditions may not provide appropriate support to people who also have learning disabilities. For example, dementia services may not cater well for people who have developed dementia in middle age.

People at end of life: This is an ageing population who may have multiple long term and terminal conditions, such as dementia. Providing end of life care which accords with their wishes, needs and comfort may be a particular challenge for services.

People with learning disability and mental health conditions: “Adults with

learning disabilities are more likely to experience psychiatric disorders than adults generally although reported prevalence varies considerably.” ([British Institute of Learning Disabilities](#)). Research suggests that people with learning disability and with mental health problems may find it difficult to access support from services that can assess both areas of need. Mental health services for this group are sometimes provided in mainstream acute services, which may not be well-equipped to offer additional support in daily care and communication; or in specialist care settings, which are more likely to be out of the person’s locality (a disadvantage in terms of maintaining relationships with friends and carers). NICE is developing a guideline on “Mental health problems in people with learning disabilities: prevention, assessment and management of mental health problems in people with learning disabilities”, expected publication date September 2016, so this current guideline will review evidence and develop recommendations, which cross refer to the guideline already in development.

People who have cognitive impairment or who lack capacity: People within this population may have profound learning difficulties, or episodic lapses in capacity to make specific decisions. People who develop dementia may lose capacity. The guideline should promote good practice in involvement, assessing capacity, providing advocacy and taking best interest decisions, in line with the Mental Capacity Act 2005, when working with this group. Consent to care or treatment should not be assumed, and the person may need additional advocacy in order to exercise the greatest possible choice and control over their care.

People with communication difficulties, and/or sensory impairment including dysphagia: People with learning difficulties are more likely than the general population to have related sensory and physical impairment which may impede communication with carers. Communication strategies, quality of services, choice and control, and safeguarding are important issues for people with communication difficulties, whatever their cause. Sensory impairment and communication difficulties, including profound deafness (and possible use of BSL) and age-related sight degeneration, may also develop with or be exacerbated by age. Older adults with learning disabilities will also include people for whom English is not their first

language and this will represent a further challenge to communication and involvement.

People who live alone: Older people with learning disabilities may be living at home with ageing parents. When the parents die, the person may struggle to care for themselves independently, especially if they are not known to services. The focus on older people suggests the likelihood that care and support needs will increase with time. People who live alone may then be particularly vulnerable to unmet need in all aspects of daily living.

Homeless people: This population may be particularly vulnerable to becoming homeless, if they are not adequately supported to maintain their homes and tenancies, with disastrous consequences for their health and wellbeing.

People in contact with the criminal justice system: People with learning disability may be in contact with the criminal justice system either as victims of crime or harassment, or as suspects. In either situation, they are likely to need support and advocacy at all stages to represent their interests, to be seen as credible witnesses and to ensure they are treated fairly.

People in prison: Older people with learning difficulties may be over-represented in the prison population, which is known to be ageing. Where evidence is available, the support needs of this group will be considered as Local Authorities have responsibility for their wellbeing (Care Act, 2014).

Older old people: The scope does not specify an age at which people are deemed 'older', as some people will develop age-related conditions from their 40s. However, it may be that the needs of the very old and frail will vary from those who are chronologically younger. The guideline will pay attention to this possibility, and consider whether recommendations should be different for this group.

Family carers and other supportive carers: Since learning disability is apparent in childhood, it is common for primary carers of people with learning disability and

support needs to derive much of their support from parents. Parents supporting an older person with learning disability are now likely to be aged around 70 or older themselves. As family carers themselves age, they are likely to have increasing support needs of their own, and may no longer be able to provide care for the person they care for. They may also be anxious to establish future and contingency plans for care and support of the person they care for when this is no longer possible. The death of a family member who is a primary carer may threaten many aspects of the person's wellbeing.

The needs of family carers for assessment and support in their own right (Care Act, 2014), and the continued review of their capacity to care, are important to this topic. Carers needing support may also include siblings, spouses, children and friends, and the guideline will consider this. There is some evidence of stereotyping that suggests that family members, especially women, and ethnic minority carers, are more likely to be expected to provide unpaid care than their male/white counterparts. Such assumptions should be avoided.

1.2 What is the preliminary view on the extent to which these potential equality issues need addressing by the Committee? For example, if population groups, treatments or settings are excluded from the scope, are these exclusions justified – that is, are the reasons legitimate and the exclusion proportionate?

There are few exclusions within the scope, although there is a requirement that the population have a learning disability (alongside any other conditions) and are considered to be 'older' (a relative term). People with a disorder on the autistic spectrum are included only if they have in addition a learning disability (otherwise people with Asperger's Syndrome, for example, would be included even though they do not have a learning disability). Clinical treatment of medical conditions is outside the scope of this guidance.

Plans for dealing with these aspects include sensitivity to equality and diversity issues, and search strategies specifically oriented to seek out material on these groups. The identified groups may have difficulty accessing general care services

because service personnel see people with learning disabilities as needing specialist support. The guideline will address the organisation and delivery of services that can work 'across silos', including the provision of appropriate advice and information to support access to personalised services. The guideline will attempt to uncover and address some of the areas where there is well-documented discrimination. The Guideline Committee may also make recommendations specifically in relation to particular service users and carers.

Completed by Developer: Amanda Edwards (NCCSC Director) and Margaret Lally (Chair of Guideline Committee)

Date: 26th October 2015

Approved by NICE quality assurance lead _____ Jane Silvester, Associate Director Social Care Guidelines and QA _____

Date _____ 16 December 2015 _____

2.0 Scope: after consultation (To be completed by the developer and submitted with the final scope)

2.1 Have any potential equality issues been identified during consultation, and, if so, what are they?

Yes, stakeholders requested that specific reference should be made in the scope to older people with learning disabilities and sensory impairments.

Stakeholders also argued for 'dysphagia' to be added to the considerations around people with communication difficulties.

2.2 Have any changes to the scope been made as a result of consultation to highlight potential equality issues?

Yes, section 3.1, key facts and figures has been amended and now describes how

older people with learning disabilities are far more likely than the general population to have sensory impairment, including difficulties with sight and hearing. Dysphagia has not been added to the scope although it has been added to section 1.1 of the EIA, which now reads “People with communication difficulties and/ or sensory impairment, including dysphagia”.

2.3 Is the primary focus of the guideline a population with a specific disability-related communication need?

If so, is an alternative version of the ‘Information for the Public’ document recommended?

If so, which alternative version is recommended?

The alternative versions available are:

- large font or audio versions for a population with sight loss;
- British Sign Language videos for a population who are deaf from birth;
- ‘Easy read’ versions for people with learning disabilities or cognitive impairment.

Yes, the population for this guideline is older people with learning disabilities who are more likely to have communication difficulties and also sensory impairments, including sight loss.

3.0 Guideline development: before consultation (to be completed by the developer before draft guideline consultation)

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

3.2 Have any **other** potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the Committee addressed them?

3.3 Were the Committee's considerations of equality issues described in the consultation document, and, if so, where?

3.4 Do the preliminary recommendations make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

3.5 Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

3.6 Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 3.1, 3.2 or 3.3, or otherwise fulfil NICE's obligation to advance equality?

4.0 Final guideline (to be completed by the Developer before GE consideration of final guideline)

4.1 Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them?

4.2 If the recommendations have changed after consultation, are there any recommendations that make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

4.3 If the recommendations have changed after consultation, is there potential for the recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

4.4 If the recommendations have changed after consultation, are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 4.2, 4.3 and 4.4, or otherwise fulfil NICE's obligations to advance equality?

4.5 Have the Committee's considerations of equality issues been described in the final guideline document, and, if so, where?

5.0 After Guidance Executive amendments – if applicable (To be completed by appropriate NICE staff member after Guidance Executive)

5.1 Outline amendments agreed by Guidance Executive below, if applicable:

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