

# 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 required to have an additional learning disability (as people with Asperger's Syndrome, for example, would otherwise be included although they may not have 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.

## **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?

**People who are not known to care services:** This was addressed in draft recommendation 1.2.2, which recommended that 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. It is also considered that recommendation 1.2.14, concerning easier access to transport for older people with learning disabilities, by making use of resources that are available to a wide range of people, would include older people with learning disabilities who are not yet known to care services.

**LGBT people:** Although the issue of specific service provision for LGBT people is not addressed in the recommendations or the research recommendations, the overarching principles do stress that older people with learning disabilities should have the same access to care and services as everyone else, irrespective of a number of factors, including gender reassignment and sex and sexual orientation (1.1.1). The section on planning and reviewing care and support stresses the importance of doing so in a person centred way, tailoring care and support to the person's, needs, wants and capabilities (1.4.1), and taking 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 (1.4.6).

**People of minority ethnic background:** While there is no recommendation or research recommendation that specifically addresses how the needs of older people with learning disabilities who are of minority ethnic backgrounds should be met, the overarching principle stated in recommendation 1.1.1 is that they should have the same access to care and support as everyone else, based on their needs and irrespective of race and other aspects of their identity. Recommendation 1.2.9 does state that older people with learning disabilities should have equal access to a range of community services and options that reflect the cultural diversity of the local area,



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

and 1.1.2 states that support should be tailored to their needs, strengths and preferences. Recommendation 1.4.6 states that future planning should take account of the whole of the person's life. Finally, recommendation 1.6.2 states that practitioners providing end of life care should spend time getting to know the person, including their cultural background. This is in order that end of life care is provided in a person centred way, responding to any needs that may arise from people's preferences or cultural background.

**Gender, sexual health and ageing:** While there is no recommendation or research recommendation that specifically addresses gender and sexual health, the overarching principle stated in recommendation 1.1.1 is that older people with learning disabilities should have the same access to care and support as everyone else, based on their needs and irrespective of age, sex and other aspects of their identity. Recommendation 1.2.9 states that older people with learning disabilities should have equal access to a range of community services and options that reflect the cultural diversity of the local area and people's hopes, preferences, choices and abilities as they grow older. Recommendation 1.4.6 states that future planning should take account of the whole of the person's life.

**People with co-morbidities:** This is addressed in recommendation 1.7.3, which recommends that all staff working with older people with learning disabilities should have knowledge and skills in common health conditions to which older people with learning disabilities are predisposed, for example the earlier onset of dementia.

**People at end of life:** This is covered by section 1.6, which deals with end of life care. Additionally, research recommendation 5 concerns advance planning about end of life care, while research recommendation 8 (full guideline) concerns care and support at the end of life.

**People with learning disability and mental health conditions:** In section 1.2,

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

which deals with organising and delivering services to help people live a good life, recommendation 1.2.8 states that mental health commissioners should develop protocols to ensure that older people with learning disabilities, including the older old, have access to mainstream mental health services for older people, including dementia support, while recommendation 1.7.3 states that all staff working with older people with learning disabilities have skills and knowledge in the mental health needs of older people with learning disabilities. Research recommendation 2 proposes research into 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, and research recommendation 7 (full guideline) proposes a study of 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.

**People who have cognitive impairment or who lack capacity:** One of the guideline's overarching principles deals with decision-making, mental capacity and consent. Recommendation 1.1.8 states that it must be assumed that older people with learning disabilities have 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.

**People with communication difficulties, and/or sensory impairment including dysphagia:** Recommendation 1.7.3 recommends that that all staff working with older people with learning disabilities should have skills and knowledge in communication methods, including non-verbal communication, while 1.1.7 recommends that all 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. Recommendation 1.2.14 recommends the use of JAM (Just A Minute) cards, which could assist older people with learning disabilities with communicating to transport staff that they have a learning disability.

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

The issue is also specifically addressed with regard to end of life care in recommendation 1.7.6, that staff providing end of life care should understand the person's communication preferences and have the skills to communicate with them, possibly including the use of an augmentative communication system, and in recommendation 1.6.7, that practitioners should learn from families and carers about the person's needs and wishes during end of life care, as this is particularly important if the person with the learning disability is unable to communicate.

**People who live alone:** There is not a specific recommendation or research recommendation dealing with older people with learning disabilities who live alone. However recommendation 1.4.6 does include the person's preferences about their accommodation arrangements as part of future planning, which should be reviewed every year and whenever the person's needs or circumstances change. The recommendation states that future planning should 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.

**Homeless people:** While there is not a recommendation or a research recommendation specifically about how homeless older people with a learning disability should be supported, recommendation 1.2.4 recommends that commissioners and service providers should provide accommodation options that meet the changing needs of people with learning disabilities as they grow older, including making provisions for people without a permanent home.

**People in contact with the criminal justice system:** The guideline makes no recommendations that are specifically about older people with learning disabilities who are in the criminal justice system. However, the guideline does state that criminal justice services are among the people and services that the guideline is for.

**People in prison:** There are no recommendations or research recommendations

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

that apply specifically to older people with learning disabilities who are in prison.

**People in later old age:** There are no recommendations or research recommendations that apply specifically to people in later old age with learning disabilities. However, there are recommendations for service commissioners, specifying inclusive service provision for people in later old age. Recommendation 1.2.5 recommends that 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, including people in later old age and their family members and carers, as they grow older. Recommendation 1.2.8 recommends that mental health commissioners should develop protocols to ensure that older people with learning disabilities, including the older old, have access to mainstream mental health services for older people, including dementia support.

**Family carers and other supportive carers:** A number of recommendations include or are aimed at family carers and other supportive carers. Recommendation 1.1.6 recommends that family members, friends and carers of older people with learning disabilities should be included in being provided with accessible information about how to access services including housing options for the future. Recommendation 1.4.4 recommends being aware of the help that siblings may need to support the person, for example after a family bereavement, and giving them information about useful resources. The sections 'Planning for the future' and 'End of life care' stress the importance of involving family members when making plans, if it is appropriate or what the person wants. Research recommendation 4 proposes research into the effectiveness, cost-effectiveness and acceptability of training programmes for families of older people with learning disabilities who have or are at risk of developing dementia.

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?

No other potential equality issues have been identified through the development phase.

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

Yes, the committee talked extensively about ensuring equal access to services and information and these discussions are noted under 'other considerations' in the LETR tables.

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?

No, the committee worked hard to ensure that the recommendations would not make it more difficult for specific groups to access services.

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?

No, the committee worked hard to ensure that the recommendations would not have an adverse impact on people with disabilities, in fact this is central to the guideline.

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?

No, when reviewing the recommendations, the committee worked hard to ensure they did not create barriers or difficulties in accessing services. This is explained at length in 3.1.

#### 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?

**People with sensory impairment:** A number of stakeholders suggested that more reference should be made to early identification of visual and hearing impairments through regular checks. Reference to hearing and sight tests has been added to recommendation 1.5.17.

**People without family or friends:** A small number of stakeholders commented that there was insufficient consideration of people who did not have families or close friends who could be involved in their support. The phrase ‘family members and carers’ has been amended to ‘family members, carers and advocates’ throughout the guideline to reflect this. Recommendation 1.1.10 also highlights that some people do not have close family members, friends or carers.

**People who lack mental capacity:** This had previously been identified as an equality issue, but several stakeholders commented that this had not been covered sufficiently. Recommendation 1.1.8 has been amended to make clearer that practitioners must understand and take in to account the Mental Capacity Act 2005. Recommendation 1.4.7 makes references to Lasting Power of Attorney; this was also added to the ‘Terms used’ section to make clear that this can be made in relation to health and wellbeing, or financial affairs and property. Reference to the Mental Capacity Act has also been added to recommendation 1.7.3 on training. Responses to stakeholder comments advised stakeholders that there is a separate NICE guideline in development on Decision making and mental capacity.

**People who speak English as an additional language:** One stakeholder commented that insufficient consideration had been given to people who speak English as an additional language. Reference to language needs and interpretation has been added to recommendation 1.1.5.

**Annual Health Checks:** Stakeholders noted that Annual Health Checks were a key reasonable adjustment to address inequalities in health outcomes and access to

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

healthcare for people with learning disabilities. Recommendation 1.5.12 was therefore strengthened to an 'offer' recommendation to reflect the importance of health checks as a mechanism for addressing inequality.

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?

The Guideline Committee was careful in revising the recommendations to ensure that it would not be more difficult for any groups to access services.

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?

The Guideline Committee was careful in revising the recommendations to ensure that the recommendations would not have an adverse impact on people with disabilities.

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?

As noted above, several recommendations have been amended in order to better address barriers to services, in particular 1.1.5, 1.1.8, 1.1.10, 1.5.17 and 1.7.3.



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

Consideration of equality issues is documented in the Linking Evidence to Recommendations tables in the full guideline.