

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Guideline scope

### Care and support of older people with learning disabilities

#### *Topic*

The Department of Health in England has asked NICE to produce a guideline on care and support of older people with learning disabilities.

For more information about why this guideline is being developed, and how the guideline will fit into current practice, see the [context](#) section.

#### *Who the guideline is for*

- providers of social care, health and housing support for older people with learning disabilities
- social care, health and housing practitioners supporting older people with learning disabilities

It will also be relevant to:

- older people with learning disabilities, families and carers
- commissioners of care and support for older people with learning disabilities
- people with a strategic role in assessing and planning local services
- practitioners working in other related services, including:
  - older people's services
  - adult learning disability services
  - employment, education and criminal justice services.

1 NICE guidelines cover health and care in England. Decisions on how they  
2 apply in other UK countries are made by ministers in the [Welsh Government](#),  
3 [Scottish Government](#), and [Northern Ireland Executive](#).

#### 4 ***Equality considerations***

5 NICE has carried out [an equality impact assessment](#) [add hyperlink in final  
6 version] during scoping. The assessment:

- 7 • lists equality issues identified, and how they have been addressed
- 8 • explains why any groups are excluded from the scope, if exclusions were  
9 made.

## 10 **1 What the guideline is about**

### 11 **1.1 Who is the focus?**

#### 12 **Groups that will be covered**

- 13 • All older people with learning disabilities<sup>1</sup> and care and support needs  
14 (irrespective of whether they are known to health and social care services).

15 A specific age limit will not be used to define older people because adults with  
16 learning disabilities typically experience age-related difficulties at different  
17 ages, and at a younger age than the general population.

#### 18 **Groups that will not be covered**

- 19 • Older people on the autistic spectrum disorder who do not have a learning  
20 disability

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<sup>1</sup> The guideline will use the definition of 'learning disability' found in [Valuing People](#) (Department of Health, 2001). In [Valuing People](#) a learning disability is defined as 'a significantly reduced ability to understand complex information or learn new skills (impaired intelligence); a reduced ability to cope independently (impaired social functioning); a condition which started before adulthood (18 years of age) and has a lasting effect'. The term learning disability in this guideline implies pervasive or global learning disabilities affecting most aspects of social functioning, and not specific learning disabilities (for example dyslexia).

## 1 **1.2 Settings**

### 2 **Settings that will be covered**

3 All settings where care and support is provided to older people with learning  
4 disabilities, including:

#### 5 **Community settings**

- 6 • People's own homes, family homes and temporary accommodation such  
7 as hostels and respite arrangements.
- 8 • Supported living, such as KeyRing Network and Shared Lives schemes.
- 9 • Day services including leisure services, centres for education and  
10 employment support schemes.
- 11 • Specialist accommodation or with a housing scheme manager such as  
12 extra care housing.
- 13 • Primary healthcare, outpatients and day hospitals.

#### 14 **Care homes**

- 15 • Residential and nursing care homes (including hospices)

#### 16 **Inpatient settings**

- 17 • Acute (general and mental health) and community hospitals.

18

## 19 **1.3 Activities, services or aspects of care**

### 20 **Key areas that will be covered**

- 21 1 Identification, assessment and regular review of health and social care  
22 needs in older people with learning disabilities and assessment of their  
23 carers' needs. This will include identification of health and social care  
24 needs specifically related to ageing.
- 25 2 Information, advice, training and support for older people with learning  
26 disabilities and their families, carers and advocates to enable and  
27 promote involvement, choice and control.

- 1 3 Interventions to support access and referral to health and social care  
2 services, including screening, health checks and advocacy (including  
3 self-advocacy).
- 4 4 Care and support planning and crisis and risk management for older  
5 people with learning disabilities, including joint working with housing,  
6 employment, education and related services to ensure:
- 7 – Development of initial care plan following assessment
  - 8 – Ongoing review of changing needs, crisis management, contingency  
9 and future planning.
- 10 5 Interventions and elements of care and support for older people with  
11 learning disabilities, including the provision of:
- 12 – Personal care including help with washing, dressing and nutrition
  - 13 – Support to prevent and manage chronic health conditions and to  
14 adopt and maintain healthy lifestyle choices
  - 15 – Practical and emotional support (for example, relating to finances,  
16 retirement, bereavement and life changes)
  - 17 – Support to develop and maintain relationships by enabling access to  
18 volunteering, social and leisure activities, transport and technology
  - 19 – Support to access mainstream services in the community
  - 20 – Housing-related support
  - 21 – Employment support, training and further education
  - 22 – Safeguarding
  - 23 – Care and support at the end of life.
- 24 6 Training of health and social care staff to identify and manage the care  
25 needs of older people with learning disabilities, including common health  
26 conditions and communication and support needs.
- 27 7 Service planning and organisation for older people with learning  
28 disabilities, including:
- 29 – Age-appropriate service planning and configuration
  - 30 – Types of age-appropriate service provision and accommodation
  - 31 – Systems to identify and record numbers of older people with learning  
32 disabilities.

1 **Areas that will not be covered**

2 1 Clinical treatments for, and management of, medical conditions.

3 **1.4 Economic aspects**

4 We will take cost-effectiveness into account when making recommendations.

5 We will develop an economic plan that states for each review question  
6 whether economic considerations are relevant, and if so whether this is an  
7 area that should be prioritised for economic modelling and analysis. We will  
8 review the economic evidence and carry out economic analyses, using a  
9 public sector perspective. However, a societal perspective may also be  
10 adopted to test the sensitivity of the results when including other relevant  
11 costs and outcomes related to people using services and their carers.

12 **1.5 Key issues and questions**

13 While writing this scope, we have identified the following potential review  
14 questions:

- 15 1 What are the views and experiences of older people with learning  
16 disabilities and their carers about how health and social care needs are  
17 identified, assessed and reviewed?
- 18 2 What are the views and experiences of health, social care and other  
19 practitioners about how the health and social care needs of older people  
20 with learning disabilities and their carers are identified, assessed and  
21 reviewed?
- 22 3 What is the effectiveness and cost effectiveness of providing information,  
23 advice and training to older people with learning disabilities?  
24 – What are the views and experiences of older people with learning  
25 disabilities about information, advice and training?  
26 – What are the views and experiences of health, social care and other  
27 practitioners about information, advice and training for older people  
28 with learning disabilities?
- 29 4 What is the effectiveness and cost effectiveness of providing information,  
30 advice, training and support to families, carers and advocates of older  
31 people with learning disabilities?

- 1 – What are the views and experiences of carers about information,  
2 advice, training and support provided to families, carers and  
3 advocates?
- 4 – What are the views and experiences of health, social care and other  
5 practitioners about information, advice, training and support for  
6 families, carers and advocates?
- 7 5 What is the effectiveness and cost effectiveness of interventions or  
8 approaches to improve access and referral to health and social care  
9 services for older people with learning disabilities?
- 10 – What are the views and experiences of older people with learning  
11 disabilities and their carers about interventions or approaches to  
12 improve access and referral to health and social care services?
- 13 – What are the views and experiences of health, social care and other  
14 practitioners about interventions or approaches to improve access  
15 and referral to health and social care services for older people with  
16 learning disabilities?
- 17 6 What is the effectiveness and cost effectiveness of care planning and  
18 support for older people with learning disabilities to access mainstream  
19 services and develop and maintain relationships with family, friends and  
20 within their local community?
- 21 – What are the views and experiences of older people and their carers  
22 in relation to support for developing and maintaining relationships with  
23 family, friends and the local community?
- 24 – What are the views and experiences of health, social care and other  
25 practitioners about support for older people with learning disabilities to  
26 develop and maintain relationships with family, friends and the local  
27 community?
- 28 7 What is the effectiveness and cost effectiveness of care and support at  
29 home, in supported housing and in accommodation with care and  
30 support for older people with learning disabilities?
- 31 – What are the views and experiences of people using services and  
32 their carers in relation to care at home, in supported housing or

- 1 accommodation with care and support for older people with learning  
2 disabilities?
- 3 – What are the views and experiences of health, social care and other  
4 practitioners about care and support at home, in supported housing or  
5 accommodation with care and support for older people with learning  
6 disabilities?
- 7 8. What is the effectiveness and cost effectiveness of end of life care for  
8 older people with learning disabilities?
- 9 – What are the views and experiences of older people with learning  
10 disabilities and their carers about end of life care?
- 11 – What are the views and experiences of health, social care and other  
12 practitioners about end of life care for older people with learning  
13 disabilities?
- 14 9. What are the views and experiences of older people with learning  
15 disabilities and their carers about care and support in health settings?
- 16 10. What training is available for care and support practitioners working with  
17 older people with learning disabilities?
- 18 – What is the impact of training for care and support practitioners  
19 working with older people with learning disabilities?

## 20 **1.6 Main outcomes**

21 The main outcomes that will be considered when searching for and assessing  
22 the evidence are:

- 23 1 Person-focused outcomes:
- 24 – Independence, choice and control over daily life
- 25 – Capability to achieve desired, person-centred outcomes (which will be  
26 broadly defined and reflect the 9 areas of wellbeing set out in the Care  
27 Act 2014)
- 28 – Satisfaction with services
- 29 – Continuity of care
- 30 – Health- and social-care-related quality of life, including carer quality of  
31 life
- 32 – Years of life saved.

- 1 2 Service outcomes:
- 2 – Use of health and social care services (secondary, primary and
  - 3 community) and housing support
  - 4 – Need for support from care workers and carers
  - 5 – Delayed transfers of care from hospital
  - 6 – Hospital admissions and readmissions
  - 7 – Admissions to care homes
  - 8 – Length of stay (hospital and care homes).

## 9 **2 Links with other NICE guidance and NICE**

### 10 **Pathways**

#### 11 **2.1 NICE guidance**

##### 12 **NICE guidance about the experience of people using services**

13 NICE has produced the following guidance on the experience of people using  
14 services. This guideline will not include additional recommendations on these  
15 topics unless there are specific issues related to older people with learning  
16 disabilities.

- 17 • [Patient experience in adult NHS services](#) (2012) NICE guideline CG138
- 18 • [Service user experience in adult mental health](#) (2011) NICE guideline
- 19 CG136
- 20 • [Medicines adherence](#) (2009) NICE guideline CG76

##### 21 **NICE guidance in development that is closely related to this guideline**

22 NICE is currently developing the following guidance that is closely related to  
23 this guideline:

- 24 • [Home care](#) NICE guideline. Publication expected September 2015
- 25 • [Social care of older people with complex care needs and multiple long-term](#)
- 26 [conditions](#) NICE guideline. Publication expected November 2015

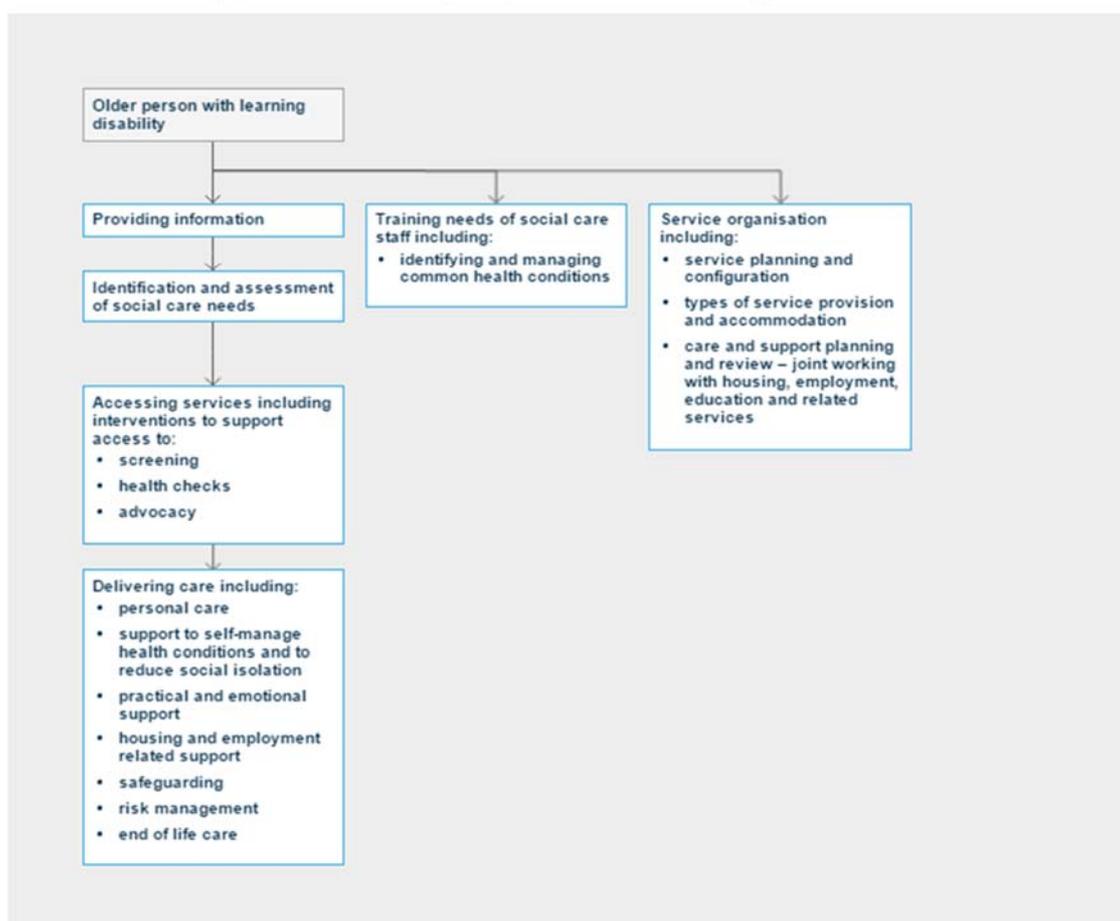
- 1 • [Transition between inpatient hospital settings and community or care home](#)  
2 [settings for adults with social care needs](#) NICE guideline. Publication  
3 expected November 2015
- 4 • [Older people – independence and mental wellbeing](#) NICE guideline.  
5 Publication expected November 2015
- 6 • [Transition between inpatient mental health settings and community and](#)  
7 [care home settings](#) NICE guideline. Publication expected August 2016
- 8 • [Mental health problems in people with learning disabilities: prevention,](#)  
9 [assessment and management of mental health problems in people with](#)  
10 [learning disabilities](#) NICE guideline. Publication expected September 2016.
- 11 • [Models of service delivery for people with learning disabilities and with](#)  
12 [behaviour that challenges](#) NICE guideline. Publication expected September  
13 2017
- 14 • [Service user and carer experience](#) NICE guideline. Publication expected  
15 January 2018.

## 16 **2.2 NICE Pathways**

17 When this guideline is published, the recommendations will be added to [NICE](#)  
18 [Pathways](#). NICE Pathways bring together all related NICE guidance and  
19 associated products on a topic in an interactive topic-based flow chart.

20 NICE has a pathway on mental wellbeing and older people and is developing  
21 pathways on older people with complex care needs and multiple long-term  
22 conditions and older people – independence and mental wellbeing. The care  
23 and support of older people with learning disabilities pathway will show clearly  
24 how they fit together. A draft pathway outline, based on the draft scope, is  
25 included below. It will be adapted and more detail added as the  
26 recommendations are written during guideline development.

## Care and support of older people with learning disabilities overview



1

2 The guideline will overlap with the existing NICE guidelines on [Autism:](#)  
 3 [recognition, referral, diagnosis and management of adults on the autism](#)  
 4 [spectrum](#) and [Challenging behaviour and learning disabilities: prevention and](#)  
 5 [interventions for people with learning disabilities whose behaviour challenges.](#)

6 The NICE Pathway will integrate the recommendations from these guidelines,  
 7 showing clearly how they fit together.

8 Other relevant NICE guidance will also be linked to from the NICE Pathway,  
 9 including:

- 10 • [Managing overweight and obesity in adults - lifestyle weight management](#)  
 11 [services](#) NICE guidelines PH53 (2014)
- 12 • [Stroke rehabilitation](#) NICE guideline CG162 (2013)
- 13 • [Diagnosis and management of the epilepsies in adults, children and young](#)  
 14 [people](#) NICE commissioning guideline CMG47 (2013)

- 1 • [Preventing type 2 diabetes: risk identification and interventions for](#)
- 2 [individuals at high risk](#) NICE guideline PH38 (2012)
- 3 • [Prevention of cardiovascular disease NICE guideline](#) PH25 (2010)

## 4 **3 Context**

5 The guideline will cover the contribution made by social care, health and  
6 housing services to the wellbeing of older people with learning disabilities. It  
7 also covers the links between those services and related areas such as  
8 criminal justice, employment, further education and training, although the  
9 remit does not extend to making recommendations specifically directed at  
10 practitioners in those fields. The focus is on improving the way that care and  
11 support practitioners work with colleagues in those related areas to maximise  
12 person-centred outcomes for older people with learning disabilities.

### 13 **3.1 Key facts and figures**

14 Older people with learning disabilities face many of the same issues as other  
15 older people, but they also face specific challenges relating to health and  
16 social needs. These are because of both lifestyle and genetic factors.

17 Some people with learning disabilities are genetically predisposed to certain  
18 health conditions in later life. For example, prevalence rates of clinically  
19 diagnosed dementia are higher for people with Down's syndrome than in the  
20 general population. The condition is also likely to develop in this population at  
21 a much earlier age, starting when they are in their 30s and steadily increasing  
22 in prevalence into their 60s. According to '[Dementia and people with learning](#)  
23 [disabilities](#)' (Royal College of Psychiatrists, 2015), nearly 70% of older adults  
24 with Down's syndrome would be likely to develop dementia symptoms if they  
25 all lived to the age of 70. In fact, all people with learning disabilities are at  
26 greater risk of developing dementia than the general population (22% versus  
27 6% aged 65 and above).

28 Older people with learning disabilities are also vulnerable to health conditions  
29 resulting from having lived unhealthy lives with poor diets, less exercise and  
30 less mobility. This leads to a greater risk of obesity and age-related diseases

1 including hypertension, diabetes, heart disease, stroke, arthritis and  
2 respiratory disease ([Royal College of Nursing, 2011](#)). Overall, older people  
3 with learning disabilities are 2.5 times more likely to experience health  
4 problems than other people ([Department of Health, 2001](#)).

5 Some older people with learning disabilities can also be at increased risk of  
6 other health problems because of their genetic make-up. For example,  
7 musculoskeletal disorders are higher among people with Fragile X syndrome  
8 and diabetes is higher among people with Prader–Willi syndrome (Royal  
9 College of Nursing, 2011).

10 As well as health problems, older people with learning disabilities also  
11 experience particular housing and social support needs. Two-thirds of adults  
12 with learning disabilities live with their families, usually their parents. Of these,  
13 40% live with a parent aged over 60 and 33% with a parent aged over 70  
14 (British Institute of Learning Disabilities, 2012). When their parents become  
15 frail, the person with a learning disability may assume a caring role and the  
16 family members may become interdependent. When their parents have died,  
17 the person with a learning disability may remain in the family home or have  
18 little choice but to move to a care home. If homes for adults with learning  
19 disabilities are unsuitable, then the person is likely to be placed in older  
20 people's residential services at a much younger age than the general  
21 population.

22 Older people with learning disabilities living in the community are often not  
23 known to health, social care or housing services; data from the Department of  
24 Health in 2001 showed that up to 25% of people with learning disabilities living  
25 with older family carers are not known to services until there is a crisis ([BILD  
26 Supporting Older People with a Learning Disability, 2014](#))

### 27 **3.2 Current practice**

28 As shown above, people with learning disabilities may continue to live with  
29 parents or relatives into adulthood and middle age. This means that their  
30 housing and support needs are met with little if any state intervention. People  
31 may live alone if this is their preference. They may also live with a partner,

1 and have children, so that support is delivered within their family unit. As  
2 people and their supportive carers age, caring relatives may die and care  
3 needs begin to escalate, and the person or their supporters may no longer be  
4 able to deliver good care. The person's established home, day-to-day support  
5 and personal care provision may all be lost, and the older person with a  
6 learning disability will need comprehensive assessment of all their current and  
7 likely future life needs, including accommodation, personal care, social and  
8 psychological needs.

9 People with learning disabilities are known to suffer health disadvantages  
10 through increased likelihood of poverty, poor housing and social exclusion.  
11 They may have difficulty in recognising their health needs and accessing  
12 appropriate support, and lead unhealthy lifestyles, in relation to diet and  
13 exercise, which may disadvantage them as they age ([BILD, 2014](#)). Ageing  
14 may then represent a traumatic range of transitions and uncertainties, and  
15 vulnerability to mental health problems may arise as housing, health and  
16 social and psychological support is disrupted.

17 Accessing health and support services may be difficult for people with learning  
18 disabilities, unless they have well-informed advocacy. There are many  
19 features that may make access to care services problematic, and some of  
20 these are more strongly associated with people with learning disabilities: for  
21 example, communication difficulties, sensory impairment, and language.  
22 Difficulties in access are compounded for people with learning disabilities, as  
23 there is variation across England in service configuration, age and other  
24 criteria for services, including community and inpatient services which offer  
25 support for adults with learning disabilities, for older people, for people with  
26 age-related mental health conditions, and appropriate support for older people  
27 with learning disabilities who have physical conditions. People with learning  
28 disabilities may be in care situations that are poorly equipped to organise  
29 transfer and support for them to move to more suitable living arrangements.

30 The [Perspectives on ageing with learning disabilities](#) paper from the Joseph  
31 Rowntree Foundation contains good evidence that people with learning  
32 disabilities want very similar opportunities to the rest of the population. For

1 example, choices, social participation with people of their own age and  
2 abilities, not to be lonely, and to maintain contact with their own familiar  
3 communities. Carers feel it is important that the person they care for is known  
4 to services, that services have all the information that they need and will  
5 ensure that the person is safe, active and happy, and that plans are in place  
6 for whatever the future may bring.

### 7 **3.3 Policy, legislation, regulation and commissioning**

#### 8 **Policy**

9 Policies relating to older people and people with learning disabilities have  
10 generally worked alongside each other. For people with learning disabilities,  
11 two of the most important policy documents are Valuing People and Valuing  
12 People Now. [Valuing People: a new strategy for the 21<sup>st</sup> century](#) was the first  
13 White Paper for people with learning disabilities in 30 years. Published in  
14 2001, the Government used Valuing People to set out their commitment to  
15 improving the life chances of people with learning disabilities including older  
16 people. Subsequently, in 2009, the Government published [Valuing People  
17 Now: a new three year strategy for people with learning disabilities](#), which  
18 updated Valuing People, set out the Government response to [Healthcare for  
19 All](#) and provided a response to the Joint Committee on Human Rights report,  
20 A Life Like Any Other? The first autism strategy [Fulfilling and Rewarding Lives](#)  
21 is also relevant to this guideline. It was published in 2010 as a guide for public  
22 sector services to work together for all adults with autism.

23 In relation to older people, the most recent and significant policy development  
24 was the publication of the White Paper, [Caring for our Future](#). It set out the  
25 government's vision for the reformed care and support system including a  
26 continued focus on personalisation and prevention.

27 This guideline will be developed in the context of policies for older people and  
28 adults with learning disabilities, rather than either area in isolation.

## 1 **Legislation, regulation and guidance**

2 Caring for our Future was followed by the [Care Act 2014](#), which was  
3 implemented on 1 April 2015. The Act has specific implications for the  
4 population that will be covered by this guideline because it puts adult  
5 safeguarding on a legal footing, placing a number of new requirements on  
6 local authorities. These include setting up Safeguarding Adults Boards with a  
7 core membership of local authority, the police and the NHS, specifically  
8 Clinical Commissioning Groups. In addition, regardless of whether a local  
9 authority is providing any services to the individual, the local authority must  
10 follow up concerns about actual or suspected abuse. The Care Act also  
11 recognises the key role of carers in relation to safeguarding.

12 The Care Act also has general relevance to the provision of person-centred  
13 health and social care support for all adults. For example it provides the  
14 legislation to underpin the [Better Care Fund](#), which creates a single pooled  
15 budget to incentivise the NHS and local government to work more closely and  
16 place people's wellbeing as the focus of care and support services.

17 Other relevant legislation includes:

18 The [Mental Capacity Act 2005](#), which is designed to protect and empower  
19 individuals who may lack the mental capacity to make their own decisions  
20 about care and treatment. It is a law that applies to people aged 16 and over.

21 The [Equality Act 2010](#), which built on the foundations of the [Disability](#)  
22 [Discrimination Act](#) to legally protect people from discrimination in the  
23 workplace and in wider society. Among other provisions, the Act makes it a  
24 legal requirement for public services to put reasonable adjustments in place to  
25 help people with learning disabilities use them. This is a key area for the  
26 guideline, which will review the extent to which older people with learning  
27 disabilities have access to health and social care services. The guideline will  
28 also examine evidence about supporting this population to maintain  
29 relationships with family and community, for example through access to  
30 transport and technology.

1 The Care Quality Commission regulates learning disability services and the  
2 Health Care Professions Council regulates 16 health and care professions,  
3 many of which provide care and support to older people with learning  
4 disabilities. In 2012 the Care Quality Commission carried out a programme of  
5 unannounced inspections of 150 NHS, private care and social care services  
6 for adults with learning disabilities. This was in response to the abuse case at  
7 Winterbourne View hospital. Many of the identified failings were found to  
8 result from care that is not centred on the individual or tailored to their needs.  
9 This will be an important area for the guideline, which addresses issues such  
10 as the age appropriateness of services.

11 Existing guidance on care and support for older people with learning  
12 disabilities is published by national government departments ([Learning](#)  
13 [disabilities good practice project](#)), Royal Colleges ([Dementia and people with](#)  
14 [learning disabilities](#)), campaigning organisations ([Supporting people with](#)  
15 [learning disabilities: a toolkit](#)), the Social Care Institute for Excellence  
16 ([Learning disabilities and dementia](#)) and the Guidelines and Audit  
17 Implementation Network ([Guidelines on caring for people with a learning](#)  
18 [disability in general hospital settings](#)).

19 This guideline will develop recommendations for practice across the broad  
20 spectrum of care and support, recognising the specific needs of adults with  
21 learning disabilities as they experience the physical, social and emotional  
22 aspects of ageing.

### 23 **Commissioning**

24 Commissioners of services for older people with learning disabilities have a  
25 duty to address the health inequalities experienced by this population. Since  
26 many of the determinants of inequalities are beyond the reach of healthcare,  
27 local authority commissioners need to work with clinical commissioning  
28 groups to plan appropriate services. This is achieved through Health and  
29 Wellbeing Boards, which produce a Joint Strategic Needs Assessment for  
30 current and future health and social care needs of the local population.  
31 Crucially this should involve gathering information about people not known to  
32 services. Analysis has found that only 8% of reviewed Joint Strategic Needs

1 Assessments contained a specific section on older people with learning  
2 disabilities ([Improving Health and Lives, 2012](#)). Omitting this population  
3 means they are unlikely to be prioritised in commissioning plans and service  
4 provision across England will continue to be patchy and difficult to access.

## 5 **4 Further information**

This is the draft scope for consultation with registered stakeholders. The consultation dates are 11 August 2015 to 8 September 2015.

The guideline is expected to be published in October 2017.

You can follow progress of the [guideline](#).

Our website has information about how [NICE guidelines](#) are developed.

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