

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. In line with the Care Act 2014 the guideline also covers health and health-related provision (including housing).

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 support practitioners supporting older people with learning disabilities

It will also be relevant to:

- older people with learning disabilities, and their families, carers and advocates
- commissioners of social care, health and housing 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.

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

Equality considerations

NICE has carried out [an equality impact assessment](#) during scoping. The assessment:

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

1 What the guideline is about

1.1 Who is the focus?

Groups that will be covered

- All older people¹ with learning disabilities² and care and support needs (irrespective of whether they are known to health and social care services).

Groups that will not be covered

¹ A specific age limit will not be used to define older people because adults with learning disabilities typically experience age-related difficulties at different ages, and at a younger age than the general population.

² 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).

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

1.2 Settings

Settings that will be covered

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

Community settings

- People's own homes, family homes and temporary accommodation such as hostels and respite arrangements.
- Supported living³, including KeyRing Network and Shared Lives schemes.
- Day services including leisure services, centres for education and employment support schemes.
- Specialist accommodation or accommodation with a housing scheme manager such as extra care housing.
- Primary healthcare, outpatients and day hospitals.

Care homes

- Residential and nursing care homes (including hospices)

Inpatient settings

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

³ The guideline will use the definition developed by TLAP (Think Local Act Personal) for their Care and Support Jargon Buster. Supported living is defined as “An alternative to residential care or living with family that enables adults with disabilities to live in their own home, with the help they need to be independent. It allows people to choose where they want to live, who they want to live with, how they want to be supported, and what happens in their home”.

1.3 *Activities, services or aspects of care*

Key areas that will be covered

- 1 Identification, assessment and regular review of care and support needs in older people with learning disabilities and assessment of their carers' needs and their own needs as carers. This will include identification of care and support needs specifically related to ageing.
- 2 Information, advice, training and support for older people with learning disabilities and their families, carers and advocates
- 3 Interventions to support access and referral to health, social care and housing support services, for example advocacy (including self-advocacy).
- 4 Care and support planning and crisis and risk management for older people with learning disabilities, including joint working with housing, employment, education and related services.
- 5 Interventions and elements of care and support for older people with learning disabilities, including the provision of:
 - Personal care including help with washing, dressing and nutrition
 - Support to prevent and manage chronic health conditions and to adopt and maintain healthy lifestyle choices
 - Practical and emotional support (for example, relating to finances, retirement, bereavement and life changes)
 - Support to develop and maintain relationships by enabling access to volunteering, social and leisure activities, transport and technology
 - Support to access mainstream services in the community
 - Housing-related support including, equipment, adaptations and assistive technology.
 - Employment support, training and further education
 - Safeguarding
 - Care and support at the end of life.
- 6 Service planning and organisation for older people with learning disabilities, including:
 - Age-appropriate service planning and configuration

- Types of age-appropriate service provision and accommodation
- Systems to identify and record numbers of older people with learning disabilities.

Areas that will not be covered

- 1 Clinical treatments for, and management of, medical conditions.
- 2 The effectiveness and cost-effectiveness of housing models for older people with learning disabilities.

1.4 Economic aspects

We will take cost-effectiveness into account when making recommendations. We will develop an economic plan that states for each review question whether economic considerations are relevant, and if so whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out economic analyses, using a public sector perspective. However, a societal perspective may also be adopted to test the sensitivity of the results when including other relevant costs and outcomes related to people using services and their carers.

1.5 Key issues and questions

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

- 1 What are the views and experiences of older people with learning disabilities and their carers about how care and support needs are identified, assessed and reviewed?
- 2 What are the views and experiences of health, social care and other practitioners about how the health and social care needs of older people with learning disabilities and their carers are identified, assessed and reviewed?
- 3 What is the effectiveness and cost effectiveness of providing information, advice and training to older people with learning disabilities?
 - What are the views and experiences of older people with learning disabilities about information, advice and training?

- What are the views and experiences of health, social care and other practitioners about information, advice and training for older people with learning disabilities?
- 4 What is the effectiveness and cost effectiveness of providing information, advice, training and support to families, carers and advocates of older people with learning disabilities?
- What are the views and experiences of carers about information, advice, training and support provided to families, carers and advocates?
 - What are the views and experiences of health, social care and other practitioners about information, advice, training and support for families, carers and advocates?
- 5 What is the effectiveness and cost effectiveness of interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities?
- What are the views and experiences of older people with learning disabilities and their carers about interventions or approaches to improve access and referral to health, social care and housing support services?
 - What are the views and experiences of health, social care and other practitioners about interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities?
- 6 What is the effectiveness and cost effectiveness of care planning and support for older people with learning disabilities to access volunteering, social and leisure activities, transport and technology and maintain relationships with family, friends and within their local community?
- What are the views and experiences of older people and their carers in relation to support for developing and maintaining relationships with family, friends and the local community?
 - What are the views and experiences of health, social care and other practitioners about support for older people with learning disabilities to

- develop and maintain relationships with family, friends and the local community?
- 7 What is the effectiveness and cost effectiveness of care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities?
 - What are the views and experiences of people using services and their carers in relation to care at home, in supported housing or accommodation with care and support for older people with learning disabilities?
 - What are the views and experiences of health, social care and other practitioners about care and support at home, in supported housing or accommodation with care and support for older people with learning disabilities?
 8. What is the effectiveness and cost effectiveness of end of life care for older people with learning disabilities?
 - What are the views and experiences of older people with learning disabilities and their carers about end of life care?
 - What are the views and experiences of health, social care and other practitioners about end of life care for older people with learning disabilities?
 9. What are the views and experiences of older people with learning disabilities and their carers about care and support in health settings?

1.6 Main outcomes

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

- 1 Person-focused outcomes:
 - Independence, choice and control over daily life
 - Capability to achieve desired, person-centred outcomes (which will be broadly defined and reflect the 9 areas of wellbeing set out in the Care Act 2014)
 - Satisfaction with services

- Continuity of care
 - Health- and social-care-related quality of life, including carer quality of life
 - Years of life saved.
- 2 Service outcomes:
- Use of health and social care services (secondary, primary and community) and housing support
 - Need for support from health and social care practitioners and carers
 - Delayed transfers of care from hospital
 - Hospital admissions and readmissions
 - Admissions to care homes
 - Length of stay (hospital and care homes).

2 Links with other NICE guidance and NICE Pathways

2.1 NICE guidance

NICE guidance that is closely related to this guideline

- [Home care \(2015\) NICE guideline NG21](#)
- [Social care of older people with complex care needs and multiple long-term conditions \(2015\) NICE guideline NG22](#)
- [Transition between inpatient hospital settings and community or care home settings for adults with social care needs \(2015\) NICE guideline NG27](#)

NICE guidance about the experience of people using services

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

- [Patient experience in adult NHS services](#) (2012) NICE guideline CG138

- [Service user experience in adult mental health](#) (2011) NICE guideline CG136
- [Medicines adherence](#) (2009) NICE guideline CG76

NICE guidance in development that is closely related to this guideline

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

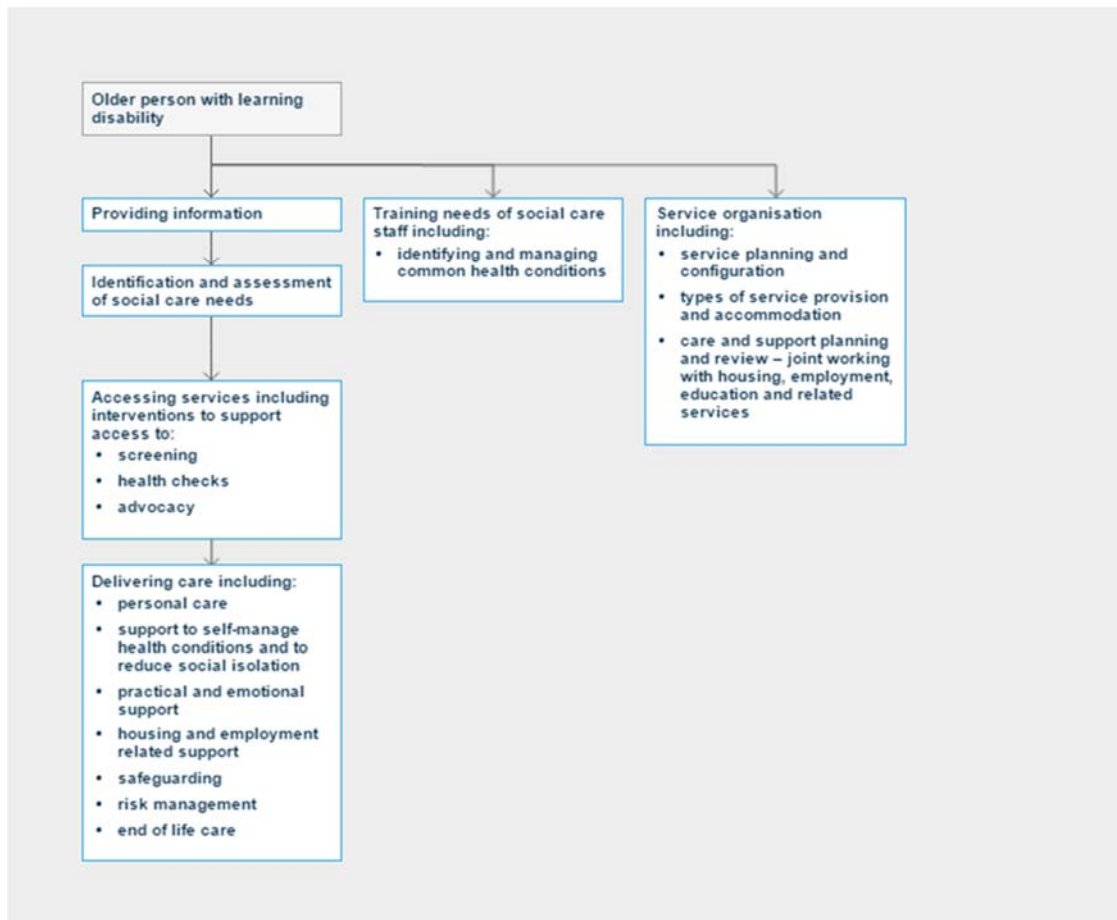
- [Older people – independence and mental wellbeing](#) NICE guideline. Publication expected November 2015
- [Transition between inpatient mental health settings and community and care home settings](#) NICE guideline. Publication expected August 2016
- [Mental health problems in people with learning disabilities: prevention, assessment and management of mental health problems in people with learning disabilities](#) NICE guideline. Publication expected September 2016.
- [Models of service delivery for people with learning disabilities and with behaviour that challenges](#) NICE guideline. Publication expected September 2017
- [Service user and carer experience](#) NICE guideline. Publication expected January 2018.

2.2 NICE Pathways

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

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

Care and support of older people with learning disabilities overview



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

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

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

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

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

3 Context

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

3.1 Key facts and figures

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

Some people with learning disabilities are genetically predisposed to certain health conditions in later life. For example, prevalence rates of clinically diagnosed dementia are higher for people with Down's syndrome than in the general population. The condition is also likely to develop in this population at a much earlier age, starting when they are in their 30s and steadily increasing in prevalence into their 60s. According to '[Dementia and people with learning disabilities](#)' (Royal College of Psychiatrists, 2015), nearly 70% of older adults with Down's syndrome would be likely to develop dementia symptoms if they all lived to the age of 70. In fact, all people with learning disabilities are at greater risk of developing dementia than the general population (22% versus 6% aged 65 and above). Practitioners may have difficulty in distinguishing between symptoms of dementia, learning disabilities and other mental health difficulties. This is known as 'diagnostic overshadowing' and can hinder

treatment, management and trust in health personnel, according to '[Equal Treatment: Closing the Gap](#)' (Disability Rights Commission, undated).

People with learning disabilities die of similar causes and conditions to those that affect the general population. However, the [Confidential Inquiry into Premature Deaths of People with Learning Disabilities](#) (CIPOLD, 2013) found that of 238 deaths identified as those of people with learning disabilities, 42% were classed as 'premature'. In context, this means that the person could have lived for at least another year but for delays or problems in diagnosis, treatment or appropriate care which was responsive to changing need. The median age of death in this cohort was 65 for men and 63 for women, considerably lower than that of the general population (78 for men, 83 for women).

Older people with learning disabilities are also vulnerable to health conditions resulting from having lived unhealthy lives with poor diets, less exercise and less mobility. This leads to a greater risk of obesity and age-related diseases including hypertension, diabetes, heart disease, stroke, arthritis and respiratory disease ([Royal College of Nursing, 2011](#)). Overall, older people with learning disabilities are 2.5 times more likely to experience health problems than other people ([Department of Health, 2001](#)). Adults with learning disabilities are far more likely to have sensory impairment compared to the general population, but are less likely to access sight, hearing and dental checks ([Health Inequalities & People with Learning Disabilities in the UK: 2012](#)), especially if they are living independently or with family. Sensory impairment is itself a barrier to social participation and access to health and care services.

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

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

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

3.2 Current practice

As shown above, people with learning disabilities may continue to live with parents or relatives into adulthood and middle age. This means that their housing and support needs are met with little if any state intervention. People may live alone if this is their preference. They may also live with a partner, and have children, so that support is delivered within their family unit. As people and their supportive carers age, caring relatives may die and care needs begin to escalate, and the person or their supporters may no longer be able to deliver good care. The person's established home, day-to-day support and personal care provision may all be lost, and the older person with a learning disability will need comprehensive assessment of all their current and likely future life needs, including accommodation, personal care, social and psychological needs.

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

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

The [Perspectives on ageing with learning disabilities](#) paper from the Joseph Rowntree Foundation contains good evidence that people with learning disabilities want very similar opportunities to the rest of the population. For example, choices, social participation with people of their own age and abilities, not to be lonely, and to maintain contact with their own familiar communities. Carers feel it is important that the person they care for is known to services, that services have all the information that they need and will ensure that the person is safe, active and happy, and that plans are in place for whatever the future may bring.

3.3 Policy, legislation, regulation and commissioning

Policy

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

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

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

Legislation, regulation and guidance

Caring for our Future was followed by the [Care Act 2014](#), which was implemented on 1 April 2015. The Act has specific implications for the population that will be covered by this guideline because it puts adult safeguarding on a legal footing, placing a number of new requirements on local authorities. These include setting up Safeguarding Adults Boards with a core membership of local authority, the police and the NHS, specifically Clinical Commissioning Groups. In addition, regardless of whether a local

authority is providing any services to the individual, the local authority must follow up concerns about actual or suspected abuse. The Care Act also recognises the key role of carers in relation to safeguarding.

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

Other relevant legislation includes:

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

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

The Care Quality Commission regulates learning disability services and the Health Care Professions Council regulates 16 health and care professions, many of which provide care and support to older people with learning disabilities. In 2012 the Care Quality Commission carried out a programme of unannounced inspections of 150 NHS, private care and social care services for adults with learning disabilities. This was in response to the abuse case at Winterbourne View hospital. Many of the identified failings were found to result from care that is not centred on the individual or tailored to their needs.

This will be an important area for the guideline, which addresses issues such as the age appropriateness of services.

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

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

Commissioning

Commissioners of services for older people with learning disabilities have a duty to address the health inequalities experienced by this population. Since many of the determinants of inequalities are beyond the reach of healthcare, local authority commissioners need to work with clinical commissioning groups to plan appropriate services. This is achieved through Health and Wellbeing Boards, which produce a Joint Strategic Needs Assessment for current and future health and social care needs of the local population. Crucially this should involve gathering information about people not known to services. Analysis has found that only 11% of reviewed Joint Strategic Needs Assessments contained a specific section on older people with learning disabilities ([Improving Health and Lives, 2014](#)). Omitting this population means they are unlikely to be prioritised in commissioning plans and service provision across England will continue to be patchy and difficult to access.

4 Further information

The guideline is expected to be published in 2017.

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

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