Care and support of older people with learning disabilities

NICE guideline: short version

Draft for consultation, November 2017

This guideline covers care and support of older people with learning disabilities. It covers identifying and assessing people's changing needs as they grow older, making information and services accessible, future planning and service delivery and organisation. It aims to ensure that adults with learning disabilities are given help to access services, including health, social care, housing and end of life, that will provide support as they grow older.

Who is it for?

- Providers of social care, health and housing support for older people with learning disabilities
- Social care, health and housing support practitioners who work with older people with learning disabilities and their family members and carers
- Commissioners and people with a strategic role in assessing and planning local services
- Practitioners in other related services, including older people's services, adult learning disability services, employment, education and criminal justice services
- Older people with learning disabilities, their families, carers and advocates.

This version of the guideline contains the draft recommendations, context and recommendations for research. Information about how the guideline was developed is on the guideline's page on the NICE website. This includes the

guideline committee's discussion and the evidence reviews (in the full guideline), the scope, and details of the committee and any declarations of interest.

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Context

People with learning disabilities are now living significantly longer. The population of older people with learning disabilities will increase 4 times faster than the overall adult learning disability population (People with learning disabilities in England, Emerson and Hatton 2008). Older people with learning disabilities have many of the same age-related health and social care needs as other older people but they also face specific challenges associated with their learning disability. Many older people with learning disabilities, especially those with milder disability, are not known to health or social services (People with learning disabilities in England 2013, Public Health England 2014), while others may find it difficult to express their needs and be heard. Management of their needs will therefore be more complex than for other populations. This will create substantial pressure on services which has not yet been fully quantified.

Health and social issues of older people with learning disabilities

People with learning disabilities have a poorer health profile than the general population. For example, there is a high prevalence of dementia in people with Down's syndrome. Practitioners may have difficulty distinguishing the symptoms of a condition such as dementia from those associated with learning disabilities and other mental health difficulties.

People with learning disabilities may have increased risk of mortality due to conditions associated with their learning disability (for example epilepsy and aspiration pneumonia). However, many such conditions are often diagnosed late in the course of illness. The Michael Report: Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities (2008) and the subsequent Confidential Enquiry into Premature Deaths of People with Learning Disabilities (CIPOLD, Heslop et al. 2013) identified a failure of services to take account of the needs of people with learning disabilities and make reasonable adjustments. This led to misdiagnosis and in some instances premature death.

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 or

dental checks, particularly if they are living independently or with family. Sensory impairment is also a barrier to accessing services.

Older people with learning disabilities also have particular housing and social support needs. Two-thirds of adults with learning disabilities live with their families, usually their parents. In some instances they may be caring for an older frail parent while they too are getting older. Eventually, ageing family carers may reluctantly explore alternative care arrangements when they are no longer able to provide long-term care. More serious is when family care ends through parental illness or death and, due to lack of future planning, the person is moved inappropriately.

For people living in homes designed for adults with learning disabilities, these may be considered unsuitable for them as they age, which can lead to a move. Older people with learning disabilities are thus likely to be placed in older people's residential services at a much younger age than the general population, even though this may not meet their preferences or needs, especially in regard to communication and support.

The purpose of this guideline

The purpose of this guideline is to help commissioners and providers identify, plan and provide for the health and social care needs of older people with learning disabilities and their families and carers. It covers integrated commissioning and planning; service delivery and organisation; providing accessible information, advice and support; identifying and assessing people's changing needs; care planning; and supporting access to services including health, social care, housing and end of life care. It aims to ensure that older people with learning disabilities are given the help they need to access a range of services as they reach old age so they can live healthy and fulfilled lives.

The guideline covers care and support in all settings, including people's homes and family homes, temporary accommodation, supported living (including Key Ring Network and Shared Lives Schemes) and specialist accommodation. It also covers day services, residential and nursing homes and primary and secondary healthcare.

A specific age limit is not used in this guideline because adults with learning disabilities typically experience age-related difficulties at different ages, and at a younger age than the general population. The guideline does not cover older people on the autistic spectrum who do not have a learning disability.

More information

To find out what NICE has said on topics related to this guideline, see our web page on older people and people with learning disabilities.

Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

1.1 Overarching principles

Access to services and person-centred care

1.1.1 Ensure older people with learning disabilities have the same access to care and support as everyone else, based on their needs and irrespective of:

- age
- disability
- gender reassignment
- marriage and civil partnership
- pregnancy and maternity
- race, religion and belief
- sex and sexual orientation

- socioeconomic status
- other aspects of their identity.

[This recommendation is adapted from the NICE guideline on service user experience in adult mental health.]

1.1.2 Give older people with learning disabilities care and support that is tailored to their needs, strengths and preferences and is not determined solely by their age or learning disability.

1.1.3 Service providers and commissioners must make reasonable adjustments to health, social care and housing services to ensure they are fully accessible to older people with learning disabilities and their family members and carers, in line with the Equality Act 2010.

1.1.4 Recognise that older people with learning disabilities may be carers, but may not see themselves as such. Ask the person if they have caring responsibilities and, if so, offer them a carer's assessment to meet their needs[1].

[This recommendation is adapted from the NICE guideline on older people with social care needs and multiple long-term conditions.]

Communicating and making information accessible

1.1.5 Practitioners must support people's communication needs and information preferences in line with NHS England's Accessible Information Standard. This includes:

- Finding out before an appointment how the person prefers to communicate and receive information.
- Extending appointment times to give more time for discussion.
- Giving people written information (such as appointment letters and reminders) in an accessible format of their choice, for example Easy

[1] NICE's guideline on provision of support for adult carers is in development and is due to be published in July 2019.

Read, audio books, films or by using online resources such as specialist learning disability websites.

- Providing information on advocacy services and, if the person needs it and consents to it, providing an independent advocate who will attend appointments.
- Using visual aids and short, clear sentences during consultations and conversations.
- Talking to the person's family members and carers, if appropriate and with the person's consent.

1.1.6 Give older people with learning disabilities and their family members and carers accessible information about:

- the range and role of different health services (such as health checks and screening)
- how to access health, social care and support services
- the community and specialist services that are available, and their purpose
- housing options that they could think about for the future.

1.1.7 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. This should usually be when:

- other needs are being assessed, for example during general health and dental checks
- there is reason to believe their communication needs may have changed.

Decision-making, mental capacity and consent

1.1.8 Assume that older people with learning disabilities have mental 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. Assess the person's capacity for each decision and carry out this assessment where and with whom the person wishes[2].

Involving people and their family members and carers

1.1.9 Health and social care practitioners should listen to, actively involve and value key members of the person's support network in the planning and delivery of their current and future care and support, if the person agrees to this. Regularly check people's willingness and ability to be involved in this way.

1.1.10 Ask the person who they want to involve if they do not have close family members. Ensure they are aware of their right to an advocate and how to access this support.

1.1.11 Find out and prioritise the needs and preferences of the person. Ensure these are not overshadowed by the decisions or preferences of others, including when the person lacks capacity.

1.1.12 Be aware that older people with learning disabilities may need support to communicate their needs or retain information. With the person's consent, share information with their family members and carers, for example about:

- any changes that might be needed to their care and support
- symptoms, management and prognosis of the person's health conditions.

1.2 Organising and delivering services to help people live a good life

Planning and commissioning local services

1.2.1 Health and social care commissioners should have an understanding of the needs of older people with learning disabilities in their area and know

[2] NICE's guideline on decision making and mental capacity is in development and is due to be published in May 2018. This guideline will cover supporting people to make decisions, assessing mental capacity and best interests decision-making.

what mainstream and specialist services are available locally to support people as they grow older.

1.2.2 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. This could be done by encouraging GPs to develop and maintain registers of people with learning disabilities and getting information from other support services, including education and the Department for Work and Pensions.

1.2.3 Commissioners and service providers should ensure family members, carers and advocates of older people with learning disabilities have age-appropriate community support services and resources such as:

- day opportunities
- short respite breaks (both at home and away from home)
- family placements
- support groups for family carers, including siblings, and for older people with learning disabilities who have caring responsibilities
- a single point of contact for practical information, emotional support and signposting.

1.2.4 Commissioners and service providers should provide housing options that meet the changing needs of people with learning disabilities as they grow older. This includes:

- making reasonable adjustments to accommodate their changing physical and emotional needs
- providing equipment or housing adaptations
- ensuring accessible transport links are available to help people access local facilities
- arranging housing for older people with learning disabilities who are in unstable housing situations, for example those who are homeless or in temporary accommodation (including people seeking asylum).

1.2.5 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, as they grow older, including people in later old age and their family members and carers. These might include:

- access to advocacy services
- respite care
- in-home support (such as physical adaptations)
- supported living
- residential and nursing care which reflect gender, sexual orientation and cultural preferences.

1.2.6 Consider the use of telehealth and telecare for older people with learning disabilities, their family members and carers, and relevant partners such as GPs and adult social care services.

1.2.7 Clinical commissioning groups should identify where there are gaps in community optometry and dental services for older people with learning disabilities and address those gaps.

1.2.8 Mental health commissioners should develop protocols to ensure that older people with learning disabilities, including people in later old age, have access to mainstream mental health services for older people, including dementia support.

1.2.9 Commissioners and service providers should ensure that older people with learning disabilities have equal access to a range of community services that reflect the cultural diversity of the local area and people's hopes, preferences, choices and abilities as they grow older.

1.2.10 Commissioners and providers should establish links between specialist learning disability services and mainstream older people's services. This could be done by bringing them together to help identify gaps and inform service development, sharing information and learning, and linking into voluntary sector umbrella groups.

1.2.11 Commissioners and providers should provide opportunities for older people with learning disabilities to meet up and socialise, for instance through social clubs and support groups.

1.2.12 Commissioners and providers should ensure there is a wide range of community-based physical activity programmes available and encourage people to take part to promote their health and wellbeing. Examples include dancing, swimming, bowls, using the gym, organised walks and chair-based exercise classes.

1.2.13 Commissioners and providers should arrange accessible opportunities for older people with learning disabilities to engage in education, working and volunteering.

1.2.14 Local authorities should consider introducing schemes to make transport easier for older people with learning disabilities. For example:

- providing free travel such as London's 'Freedom pass'
- using minibuses as community transport
- starting 'buddy' schemes to enable independent travel
- developing transport especially for people living in rural locations
- schemes such as 'JAM' cards (Just A Minute) – which can be used to alert transport staff that people have a learning disability
- schemes to help people with a personal budget to travel to activities and self-advocacy groups.

1.3 Identifying and assessing care and support needs

Assessing people's need for care and support

1.3.1 Ensure that all assessments of care and support needs are person centred (NICE is publishing a guideline on people's experience in adult social care services in February 2018 which covers person-centred assessment).

1.3.2 Practitioners carrying out assessments of care and support needs should have:

- access to the person's full history (medical, social, psychological and the nature of their learning disability) **and**
- an understanding of their usual behaviour.

1.3.3 Practitioners carrying out assessments of care and support needs should be alert to any changes in the person's usual behaviour. This could include how they are communicating or their activity levels, and symptoms (such as weight loss, changes in sleeping patterns or low mood) that could show something is wrong or they are unwell.

1.3.4 When people have changing needs think about whether these changes could be age-related and do not assume they are due to the person's learning disability.

1.3.5 Practitioners conducting assessments of care and support needs should help people to think about what they want from life as they age. This should include:

- asking people how they would like to spend their time and with whom
- encouraging them to develop support networks and to build and maintain links with friends and family and with community groups – these might include social, cultural and faith-based groups.

Assessing the needs of family members and carers

1.3.6 Practitioners conducting assessments of care and support needs should take into account the needs, capabilities and wishes of families and carers. Also take into account that there may be mutual caring between older people with learning disabilities, and their family members and carers, who are likely to be older themselves and have their own support needs.

1.3.7 Practitioners must offer people who are caring for an older person with a learning disability their own carer's assessment, in line with the Care Act 2014.

1.3.8 Based on assessment, provide families and carers with support that meets their needs as carers.

1.3.9 Review the needs and circumstances of carers at least once a year and if something significant changes.

1.3.10 Actively encourage carers to register themselves as a carer, for example with their GP.

1.4 Planning and reviewing care and support

Person-centred planning and review

1.4.1 Practitioners should carry out regular person-centred planning with people who have a learning disability to address their changing needs, wants and capabilities. This includes planning for the future. Involve their family, carers and advocates as appropriate.

1.4.2 Include transport needs in people's care and support plans, to help them get to services, appointments and activities.

1.4.3 Local authorities should plan people's care and support in a way that meets the needs of all family members, as well as the older person with a learning disability. This might include combining the personal budgets of different family members.

1.4.4 Give families and carers, including siblings, help in planning and providing support for the older person with a learning disability. For example, signposting people to resources about how to support people after a family bereavement.

Planning for the future

1.4.5 Health and social care practitioners should work with the person and those most involved in their support to agree a plan for the person's future. Help them to make decisions before a crisis point or life-changing event is reached (for example, the death of a parent or a move to new housing).

1.4.6 Planning for the future should:

- be proactive
- be led by the person themselves with input from family members, carers and advocates as appropriate (regardless of whether they provide care and support themselves)
- involve a practitioner who has a good relationship with the person and communicates well with them
- involve practitioners who have good knowledge of local resources
- take 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
- include considering the needs of family members and carers
- seek to maintain the person's current support and housing arrangements, if this is their preference
- be reviewed every year and whenever the person's needs or circumstances change.

1.4.7 Include as key components of a future plan:

- Housing needs and potential solutions.
- Any home adaptations or technology that may address people's changing needs as they grow older.
- Members of the person's support network (both paid and unpaid).
- Any help the person gives to other family members, whether this will continue as they age, and the impact this may have on their health and wellbeing.
- Financial and legal issues, for example whether someone has been appointed to have lasting power of attorney for the person.
- Planning for unexpected changes or emergencies
- Consideration of deprivation of liberty safeguards, for instance if planned changes to care or the care environment are likely to increase restrictions on the person.

- End of life care decisions – including where the person wants to be when they die. These decisions should be reviewed at least once a year.

Future housing

1.4.8 When helping the person plan where they will live in the future and who they will live with, take into account whether other family members rely on them for support.

1.4.9 Encourage and support people to be active and independent at home regardless of their age or disability. This might include doing household tasks, making their own decisions and plans or leading group activities.

1.4.10 Make reasonable adjustments to people's homes as they grow older to make it possible for them to stay in their current home if they want to. For example, consider a support phone line, daily living equipment, telehealth monitoring and home adaptations, such as shower room conversion, wider doorways or a lift between floors.

1.4.11 Review the housing needs of people who are being supported by social care staff at home at least once a year.

1.4.12 Ensure that an advocate or, if appropriate, a family member or carer is centrally involved in decisions about whether a person should move from supported living to residential care.

1.4.13 If a move into residential care is agreed with the person, practitioners should work with them and their support network to start planning for this straightaway. Planning could include:

- arranging for the person to visit the residential setting
- discussing how they will maintain their existing support networks and develop new ones.

1.5 Identifying and managing health needs

1.5.1 Healthcare practitioners should encourage older people with learning disabilities to choose a family member or carer to bring with them to medical examinations and appointments if they would like this support.

1.5.2 Explain clearly to older people with learning disabilities what will happen during any medical appointments as well as their likely follow-up care. In line with the Mental Capacity Act 2005, healthcare practitioners must take all reasonable steps to help the person understand this explanation.

1.5.3 As well as explaining to people beforehand what will happen, continue to explain what is happening throughout the appointment and ensure there is enough time set aside to do this. If the person agrees, also explain to their family members and carers what will happen.

1.5.4 If the person needs a medical examination give them a choice, wherever possible, about where it takes place. Aim to do it in a place that is familiar to them, which is welcoming and appropriate to their needs.

1.5.5 Support family members and carers, for example by providing information, to enable older people with learning disabilities to access health services.

1.5.6 Consider training for people and their family members and carers in recognising and managing age-related conditions such as:

- hearing loss and sight problems
- blood pressure and cholesterol
- prostate cancer
- epilepsy
- diabetes
- osteoporosis
- thyroid problems
- menopausal symptoms
- mental health, including depression and dementia.

Coordinating care and sharing information

1.5.7 Managers in healthcare settings should identify a single lead practitioner to be the point of contact for older people with learning disabilities and their family members and carers. This practitioner could be a member of the community learning disability team or a nurse with experience in learning disabilities.

1.5.8 Ensure that everyone involved in the person's care and support shares information and communicates regularly about the person's health and any treatment they are having, for example by holding regular multidisciplinary meetings. Involve the person in all discussions.

1.5.9 Primary and secondary healthcare teams should identify at least 1 member of staff who develops specific knowledge and skills in working with older people with learning disabilities and acts as a champion, modelling and sharing good practice. Use the expertise of older people with learning disabilities to ensure the champion understands their needs.

1.5.10 Record a person's learning disability in their health records. With the person's consent, make sure all healthcare practitioners in community and acute settings can access this. Also record any specific needs or wishes, for example to do with the person's communication or mobility.

Health checks and screening

1.5.11 Offer older people with learning disabilities the same routine screening and health checks as other older people.

1.5.12 Recognise that older people with learning disabilities may need additional health surveillance to help them identify and communicate symptoms of age-related conditions. This could include providing information about annual health checks, including what they involve and how to arrange them.

1.5.13 Discuss with people changes that may occur with age. Ask them about and monitor them for symptoms of common age-related conditions, including:

- hearing loss and sight problems
- blood pressure and cholesterol
- prostate cancer
- epilepsy
- diabetes
- osteoporosis
- thyroid problems
- menopausal symptoms.
- mental health, including depression and dementia (also see recommendations 1.5.36 and 1.5.37).

1.5.14 If the person is having an annual health check, give them information about other available services, including a care and support assessment under the Care Act 2014 if they have not already had one.

1.5.15 If the person is having an annual health check, ask if they are registered with a dentist, how often they see the dentist and check that they understand the importance of looking after their teeth and mouth.

1.5.16 Give people clear, accessible and practical information and advice about keeping well as they grow older. Tell them about, and help them to access, preventative services such as breast screening, smear tests, testicular and prostate checks and dental checks.

1.5.17 When designing and delivering breast screening services, address specific barriers to accessing breast screening among older women with learning disabilities, including support to:

- understand breast cancer
- understand the screening procedure
- perform breast self-examination
- understand any information provided
- attend appointments.

Primary care

1.5.18 Design primary care and community services so that older people with learning disabilities can see the same GP and other healthcare practitioners, wherever possible, to help practitioners:

- become familiar with the person's medical history, which the person may have difficulty remembering themselves
- build good relationships and understand the person's usual behaviour and communication needs.

1.5.19 General practices should allocate a named member of staff to remind older people with learning disabilities about appointments for screening and health examinations. This staff member should help the person attend the appointment by:

- using each person's preferred method of communication
- giving them information in a way they can understand
- ensuring the person understands the reason for the appointment and why it is important
- finding out their transport needs
- making reasonable adjustments to help the person and their carer or supporter to attend.

1.5.20 If the person is diagnosed with a health condition give them, and their family members and carers, accessible information on the following (taking time to explain it to them as well):

- symptoms and management
- benefits, and potential side effects, of treatment
- how to take their prescribed medicines.

1.5.21 Support older people to manage their own health conditions by getting to know them and adapting health advice to suit their personal choices and the activities they already enjoy (for example, playing football).

Dental care

1.5.22 Commissioners and managers should ensure support staff have knowledge of oral health so they can support older people with learning disabilities to maintain good oral health and access dental services.

1.5.23 Dental practices should ensure their services are accessible to older people with learning disabilities, for example by:

- reminding people about their appointments by phone
- sending letters in an accessible format, for example Easy Read
- suggesting that the person brings a carer or supporter with them
- ensuring staff have the skills to communicate with people with learning disabilities and put them at ease.

1.5.24 For further guidance on managing oral health see the NICE guidelines on:

- oral health promotion: general dental practice
- oral health for adults in care homes.

Outpatient appointments

1.5.25 Hospitals should arrange for the person and a family member or carer to visit the hospital before their outpatient appointment to meet the staff who will conduct any tests or examinations, see the equipment that will be used and identify what adjustments will be needed.

Before and during a hospital stay

1.5.26 When planning a hospital admission, arrange a pre-admission planning meeting, including the hospital liaison team or liaison nurse, a representative of the community learning disability team, the person and their family members and carers. At this meeting:

- complete the pre-admission documentation, which should include information from the person's hospital passport

- discuss any reasonable adjustments needed, for example, arranging for the person to visit the hospital before their admission to meet the learning disability liaison nurse who will be their contact.

1.5.27 Hospitals should actively encourage staff to use pre-admission documents and flagging systems so that all relevant hospital staff know about the person's learning disability. At discharge, review how well this is working.

1.5.28 Hospitals should develop policies and guidance to enable someone chosen by the person to stay with them throughout their inpatient stay. This should include providing facilities for them to stay overnight.

1.5.29 Hospital staff should continue to offer health and personal care (toileting, washing, nutrition and hydration) to older people with learning disabilities even if they have a family member or carer there to support them.

1.5.30 For further guidance on planning admission and admitting adults with identified social care needs to hospital, see NICE's guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.

Transfer of care from hospital

1.5.31 Invite family members, carers or advocates to pre-discharge meetings, as well as the person themselves.

1.5.32 If the discharge plan involves support from family members or carers, take into account their:

- willingness and ability to provide support
- circumstances, needs and aspirations
- relationship with the person
- need for respite.

[This recommendation is adapted from the NICE guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.]

1.5.33 Give the person (and their family members and carers) an accessible copy of their discharge plan when they are discharged, and make sure their GP has a copy within 24 hours. Make sure everyone knows what will happen next in the person's care and support.

[This recommendation is adapted from the NICE guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.]

1.5.34 After the person is discharged, the hospital learning disability liaison nurse, community learning disability teams and primary care practitioners should work together to provide ongoing support to the person to help them manage their health conditions.

1.5.35 For further guidance on discharging adults with identified social care needs from hospital, see NICE's guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.

Care and support for people living with dementia

1.5.36 Explain at an early stage to older people with learning disabilities (particularly people with Down's syndrome) and their family members or carers about the link between learning disabilities and dementia. Explain the signs of dementia, how it usually progresses and what support is available. Give people:

- printed information on dementia
- opportunities for one-to-one discussion with a professional
- advice on communication strategies for people with dementia.

1.5.37 Commissioners should ensure information is provided to family members and carers of older people with learning disabilities who are being assessed for, or have been diagnosed with dementia. Consider also providing training. Information and training might cover:

- types of dementia

- how dementia might present in people with different learning disabilities
- care pathways for different dementias
- practical steps to manage daily life
- communication skills
- how to find further advice and ongoing support, including support groups and respite services.

1.6 End of life care

Access to end of life care services

1.6.1 Give older people with learning disabilities and their family members and carers accessible information about all the potential care options available for end of life care, including hospice services.

Making sure end of life care is person centred

1.6.2 Practitioners providing end of life care should spend time getting to know the person to understand their needs. Get to know how they communicate, their cultural background, what they like and dislike, how they express pain, their health conditions and the medication they are taking. Be aware that this understanding will make it easier to identify when the person's health is deteriorating.

1.6.3 Identify who the person would like to involve in creating their end of life plan. Include the person themselves and everyone who supports them in discussions and planning.

1.6.4 Ask the person regularly who they would like to involve in discussions about their end of life plan, in case they change their mind. Do this every 6 months or more often if the person is close to the end of life.

1.6.5 Make it possible for the person to die where they wish. This might include adapting their home, working with other practitioners and advocates, and talking to other residents or family members about changes that could be made (for example, moving the person to a room on the ground floor).

Involving families and support networks

1.6.6 During end of life care planning, talk to the person and their family members and carers to understand the person's wishes and any cultural needs at the end of the person's life.

1.6.7 When providing end of life care, learn from family members and carers about the person's needs and wishes, including those associated with faith and culture, nutrition, hydration and pain management. This is particularly important if the person is unable to communicate.

1.6.8 Learning disability providers delivering care at the end of life should work collaboratively and share information with other practitioners and services involved in the person's daily life.

1.6.9 Social care providers should work in partnership with healthcare providers to share knowledge about the person and to develop expertise for end of life care.

1.6.10 Provide training, information and support for family members and carers, for example in medication, pain, nutrition and hydration, to enable the person to die where they wish to.

1.6.11 Make sure that key people in the support network have the knowledge, confidence and understanding to communicate with the person about their illness and death. This includes discussion about symptoms, pain management and preferences about resuscitation.

1.6.12 Mainstream end of life care services should make reasonable adjustments to support the person, their family members, friends and carers and other people they live with throughout palliative and end of life care and bereavement.

1.6.13 For further guidance on end of life care see NICE's guideline on care of dying adults in the last days of life.

1.7 Workforce skills and expertise

1.7.1 Managers in health and social care services should ensure that staff in older people's services have the expertise to support older people with learning disabilities from a wide range of backgrounds.

1.7.2 Managers in health and social care services should ensure that learning disability staff have the skills and understanding to support people's changing needs as they grow older. Provide this skilled support in all settings, including people's own homes.

1.7.3 Managers in health and social care services should ensure that all staff working with older people with learning disabilities have skills and knowledge in:

- communication methods, including non-verbal communication
- building good relationships with people with learning disabilities and making them feel at ease
- the physical and mental health needs of older people with learning disabilities, related to both their age and disability
- common health conditions to which older people with learning disabilities are predisposed, for example the earlier onset of dementia, ensuring that they do not confuse these with the person's learning disability or another condition.

1.7.4 Managers in health and social care services should provide opportunities for learning disability staff and practitioners working with older people to share expertise with each other as part of their knowledge and skills development.

1.7.5 Staff should know what local services are available (including housing options) so they can support older people with learning disabilities, families, carers and advocates to make informed choices about their care and support.

Workforce skills and expertise for supporting end of life care

1.7.6 Commissioners and providers of end of life care should recognise the complex needs of older people with learning disabilities. They should provide ongoing training for staff to ensure they have the expertise to provide good-quality coordinated care, enabling people to die in their own home or another place of their choice. Training should include:

- having discussions about resuscitation intentions
- finding out and responding to cultural preferences
- managing symptoms, pain and medication
- nutrition and hydration
- understanding communication preferences and being able to communicate – this might include using an augmentative communication system.

1.7.7 Provide in-service training for learning disability and palliative care practitioners so they have the skills to support people at the end of life. This might include joint study days and training of professionals by people with learning disabilities and their family members and carers.

Terms used in this guideline

Annual health check

An NHS initiative for adults and young people aged 14 and over with learning disabilities for the reason that they often need more health support and may have health conditions that would otherwise go undetected.

Family members and carers

This includes people related to the person with a learning disability and others who help to provide support for that person, for example friends. It does not cover staff who are paid to provide care or support.

Hospital passport

Hospital passports are designed to give hospital staff useful information that is not limited to illness and health. For example, it could include details about what the

person likes and dislikes, in terms of physical contact or food and drink. The idea is to help hospital staff understand how to make the person feel comfortable.

Older people with learning disabilities

For the purpose of this guideline a learning disability is defined as meeting 3 core criteria:

- lower intellectual ability (usually an IQ of less than 70)
- significant impairment of social or adaptive functioning
- onset in childhood.

A person's learning disability may be mild, moderate, severe or profound in severity. Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability. A specific age limit is not 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.

Practitioner

In this guideline 'practitioner' is used to mean a health or social care practitioner who provides care and support for older people with learning disabilities.

Support network

All the people who provide emotional and practical help to a person with a learning disability. A person's support network could include their family (including siblings), friends, carers, advocates, non-family members living with the person in supported housing and members of the person's religious community.

For other social care terms see the Think Local, Act Personal Care and Support Jargon Buster.

Putting this guideline into practice

[This section will be finalised after consultation]

NICE has produced tools and resources [link to tools and resources tab] to help you put this guideline into practice.

Some issues were highlighted that might need specific thought when implementing the recommendations. These were raised during the development of this guideline. They are:

- Ensuring integrated, person-centred care and support for older people with learning disabilities, and their families and carers. This will mean health and social care practitioners and providers involving and listening to the person and their family and carers, and agreeing a care plan that reflects their needs and aspirations. It will also mean challenging assumptions and looking beyond the person's learning disability, to provide the support needed to help them live an active, community-involved life.
- Ensuring a well-trained and supported workforce, with the knowledge needed to support older people with learning disabilities. Health and social care services are structured in a way that tends to mean practitioners work in either learning disability or older people's services, and their training and support reflects this. Moving to a workforce with expertise from across both disciplines may be challenging to achieve.
- Planning and commissioning local health and social care services to meet the needs of the local population. Commissioners need to know the extent of their population of older people with learning disabilities, and any likely future growth in this population. Learning disability services are often seen as separate from other services, but all pathways of care and support need to consider the needs of older people with learning disabilities in order to improve access and funding.

Putting recommendations into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes should be implemented as soon as possible, unless there is a good reason for not doing so (for example, if it would be better value for money if a package of recommendations were all implemented at once).

Different organisations may need different approaches to implementation, depending on their size and function. Sometimes individual practitioners may be able to respond to recommendations to improve their practice more quickly than large organisations.

Here are some pointers to help organisations put NICE guidelines into practice:

1. **Raise awareness** through routine communication channels, such as email or newsletters, regular meetings, internal staff briefings and other communications with all relevant partner organisations. Identify things staff can include in their own practice straight away.

2. **Identify a lead** with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally.

3. **Carry out a baseline assessment** against the recommendations to find out whether there are gaps in current service provision.

4. **Think about what data you need to measure improvement** and plan how you will collect it. You may want to work with other health and social care organisations and specialist groups to compare current practice with the recommendations. This may also help identify local issues that will slow or prevent implementation.

5. **Develop an action plan**, with the steps needed to put the guideline into practice, and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases.

6. **For very big changes** include milestones and a business case, which will set out additional costs, savings and possible areas for disinvestment. A small project group could develop the action plan. The group might include the guideline champion, a senior organisational sponsor, staff involved in the associated services, finance and information professionals.

7. **Implement the action plan** with oversight from the lead and the project group. Big projects may also need project management support.

8. **Review and monitor** how well the guideline is being implemented through the project group. Share progress with those involved in making improvements, as well as relevant boards and local partners.

NICE provides a comprehensive programme of support and resources to maximise uptake and use of evidence and guidance. See our into practice pages for more information.

Also see Leng G, Moore V, Abraham S, editors (2014) Achieving high quality care – practical experience from NICE. Chichester: Wiley.

Recommendations for research

The guideline committee has made the following recommendations for research. The full list of research recommendations is in the full guideline.

1 Models of care and support at home

What is the effectiveness and cost effectiveness of care and support models (for example, assistive technology) for older people with learning disabilities to enable them to live in the family home?

Why this is important

There is no evidence from studies published later than 2005 about the effectiveness of care and support models for older people with learning disabilities living in the family home, or about their experiences of that support. For example, we did not identify any evidence on the effectiveness of assistive technology for supporting older people with learning disabilities and their ageing family carers. Comparative studies are needed to evaluate the impact of different approaches, like assistive technology, on care and support for older people with learning disabilities in the family home. Resource use information, demonstrating the impact on unpaid care (whether it increases or decreases as a result of the different support models) is also needed as well as outcome data relating to families and carers. These should be supplemented by qualitative studies to explore the views and experiences of older people with learning disabilities, including those from minority backgrounds, and their families and carers in relation to different models of support.

2 Identifying health conditions

What 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?

What can mainstream and specialist health services do to facilitate:

- early identification of health conditions in older people with learning disabilities?
- equal access to health services in older people with learning disabilities?

Why this is important

Apart from studies on annual health checks, we did not find any evidence about different methods and pathways for identifying health conditions among older people with learning disabilities. There is a need for effectiveness and cost-effectiveness studies using longitudinal, comparative designs to evaluate the costs and outcomes of different approaches to identifying health conditions in older people with learning disabilities. These should be complemented by qualitative studies to explore the views and experiences of older people with learning disabilities, including those from minority backgrounds, and their families, carers and practitioners on the facilitators and barriers of these approaches. This includes their views on how, where and by whom these services should be provided.

3 Education and training programmes: self-management

What is the effectiveness and cost effectiveness of education programmes to improve information and advice and to support self-management of chronic health conditions (for example obesity, diabetes and cardiovascular disease) for older people with learning disabilities and their family members and carers?

Why this is important

Evidence suggests that older people with learning disabilities value the medical knowledge and authority of health professionals. There is a small amount of evidence that practitioners could play a greater role in providing education and advice to support self-management of health conditions in older people with learning disabilities. There is also evidence that families and carers play a central role in

supporting and advising older people with learning disabilities about their health conditions and promoting healthier lifestyle choices.

Comparative effectiveness and cost-effectiveness studies are needed to evaluate the impact of education programmes to support self-management for older people with learning disabilities. These need to be supplemented with studies exploring the views and experiences of older people with learning disabilities, including those from minority backgrounds, and their families, carers and practitioners, on the accessibility and acceptability of different approaches to supporting self-management and communicating health messages.

4 Dementia education and training programmes for family members and carers

What is the effectiveness, cost effectiveness and acceptability of training programmes (for example in the use of life story work) for families of older people with learning disabilities who have dementia or are at risk of developing it?

Why this is important

No evidence was found from studies published later than 2005 about the effectiveness and cost effectiveness of interventions or training programmes for family members and carers of older people with learning disabilities. There is some evidence that some family members and carers of older people with learning disabilities and dementia need specialist training in dementia care.

Comparative effectiveness and cost-effectiveness studies are needed to evaluate the impact of specific interventions or training programmes for families and carers of older people with learning disabilities, including for people living with conditions such as dementia. Qualitative studies are needed to explore the views and experiences of family, friends and carers of older people with learning disabilities, including those from minority backgrounds, about these training programmes.

5 Advance planning about end of life care

What is the effectiveness and cost effectiveness of advance care planning for end of life care for older people with learning disabilities, and their family members and carers?

What processes are in place to document and follow the wishes of older people with learning disabilities about their decisions on end of life care?

Why this is important

We identified no studies evaluating advanced care planning for end of life care in older people with learning disabilities, and their family members and carers. Such studies would help to determine how and what reasonable adjustments should be made to ensure that older people with learning disabilities receive appropriate care at the end of life. Longitudinal studies should have a naturalistic design with a control group to follow up families and carers who have used advanced care planning for end of life care in older people with learning disabilities.

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