

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

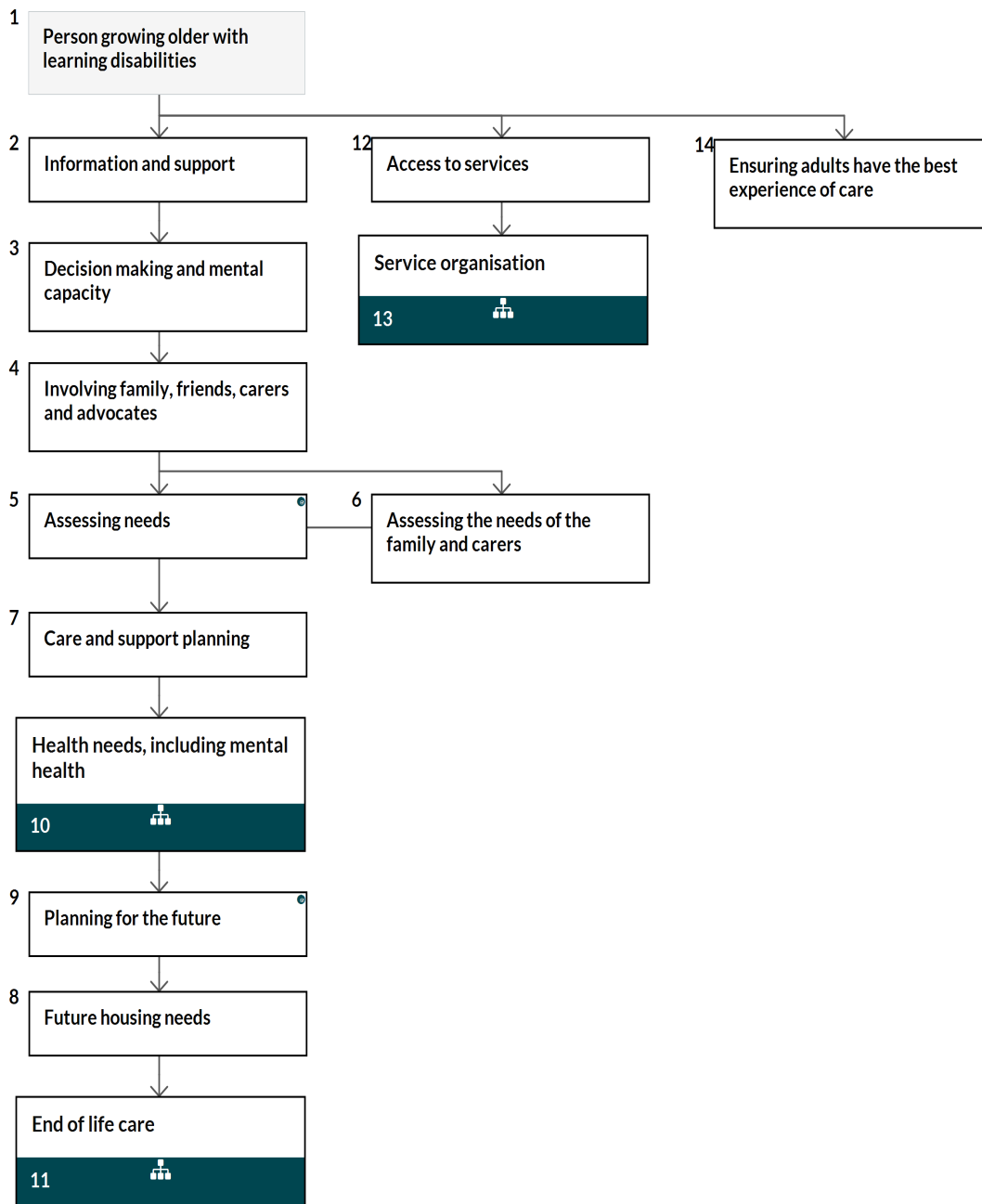
NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

They are updated regularly as new NICE guidance is published. To view the latest version of this NICE Pathway see:

<http://pathways.nice.org.uk/pathways/care-and-support-of-people-growing-older-with-learning-disabilities>

NICE Pathway last updated: 30 October 2020

This document contains a single flowchart and uses numbering to link the boxes to the associated recommendations.



## 1 Person growing older with learning disabilities

No additional information

## 2 Information and support

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

Support people's communication and information needs in line with NHS England's [Accessible Information Standard](#). This could also include:

- Seeking advice from, or referring people to, a speech and language therapist whenever needed.
- Providing an independent interpreter (that is, someone who does not have a relationship with the person) so that people can communicate in their first language.
- 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 different languages or in an accessible format of their choice, for example Easy 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.

Provide people with learning disabilities and their family members, carers and advocates with accessible, tailored 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
- planning for end of life care
- financial issues, including wills, trusts and benefits
- how to raise a safeguarding concern if they have one.

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.

### 3 Decision making and mental capacity

Health and social care practitioners must understand and take into account the [Mental Capacity Act 2005](#) when working with people with learning disabilities, including:

- assuming the person has the mental capacity to take part in decision-making unless it is established that they lack capacity
- supporting people to make decisions – finding out their views, encouraging them to take part in the decision-making process and ensuring all steps have been taken to help them express their views and make their own decisions
- assessing their capacity to make decisions – this assessment should take place where and with whom the person wishes
- undertaking best interests decision-making when it is established that a person does not have capacity to make a decision ([the NICE Pathway on decision-making and mental capacity](#) covers supporting people to make decisions, assessing mental capacity and best interests decision-making).

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.

### 4 Involving family, friends and carers and advocates

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.

Ask people who they want to involve in planning and providing their support, regardless of whether they have close family. Be aware that some people do not have close family members, friends or carers.

Offer independent advocacy whenever it is wanted or needed by a person with a learning disability. As a minimum, it must be offered as described in the [Care Act 2014](#), [Mental Capacity Act 2005](#) and [Mental Health Act 2007](#).

Be aware that 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, carers or advocate, for example about:

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

## 5 Assessing needs

Ensure that all assessments of care and support needs are strengths based, person centred and conducted as early as possible. Follow the recommendations on [assessing the person's needs in the NICE Pathway on people's experience in adult social care services](#).

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.

Practitioners carrying out 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, and enabling them to explore personal and sexual relationships
- 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.

See [assessing social care needs in the NICE Pathway on social care for older people with multiple long-term conditions](#).

### If the person is a carer

Recognise that 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 (see [the NICE Pathway on supporting adult carers](#)).

## Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

1. Person-centred needs assessment

### 6 Assessing the needs of the family and carers

Practitioners carrying out 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 people with learning disabilities, and their family members and carers, who are likely to be older themselves and have their own support needs.

Practitioners must offer people who are caring for a person with a learning disability their own carer's assessment, in line with the [Care Act 2014](#).

Based on assessment, provide families and carers with support that meets their needs as carers (see [the NICE Pathway on supporting adult carers](#)).

Review the needs and circumstances of carers at least once a year and if something significant changes (see [the NICE Pathway on supporting adult carers](#)).

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

### 7 Care and support planning

Practitioners should carry out regular person-centred planning with people growing older with learning disabilities to address their changing needs, wishes and capabilities and promote their independence. This should include planning for the future (see [housing needs \[See page 7\]](#) and [planning for the future \[See page 7\]](#)). Involve their family members, carers and advocates as appropriate.

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

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

Give help and information to families and carers, including siblings, as part of planning and providing support for people growing older with learning disabilities. For example, tell them about sources of support for people after a family bereavement.

## 8 Future housing needs

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.

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

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.

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

Ensure that the person is centrally involved in any decisions about moving from where they currently live. Also include an advocate or, if appropriate, a family member or carer.

If a move 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 new setting
- discussing how they will maintain their existing support networks and develop new ones.

## 9 Planning for the future

Health and social care practitioners should work with the person and those most involved in their support to agree a plan for the 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).

Planning for the future should:

- be proactive

- be led by the person themselves with input from family members, carers or 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.

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 family members, whether this will continue as they age, and the impact this may have on their health and wellbeing.
- Planning for what will happen if someone who the person relies on dies, or is no longer able to provide care and support.
- Financial and legal issues, for example whether someone has been appointed to have lasting power of attorney for the person.
- The provision of information on wills, trusts and benefits.
- Planning for unexpected changes or emergencies
- Planning for a time when the person may lack capacity to make decisions themselves, in line with the [Mental Capacity Act 2005](#).
- 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.

## Quality standards

The following quality statements are relevant to this part of the interactive flowchart.

### 2. Named lead practitioner



### 3. Future planning and review

## 10 Health needs, including mental health

See Care and support of people growing older with learning disabilities / Health needs of people growing older with learning disabilities

## 11 End of life care

See Care and support of people growing older with learning disabilities / End of life care for people with learning disabilities

## 12 Access to services

Ensure the people growing older with learning disabilities [See page 11] have the same access to care and support as everyone else. In line with the Equality Act 2010, this must be 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.

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.

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.

Support family members and carers, for example by providing information, so that they can help

people with learning disabilities to access health services.

### **Access to end of life care services**

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

## **13 Service organisation**

[See Care and support of people growing older with learning disabilities / Service organisation for the care and support of people growing older with learning disabilities](#)

## **14 Experience of care**

Use these recommendations with NICE's recommendations on:

- [patient experience in adult NHS services](#)
- [service user experience in adult mental health services](#)
- [people's experience in adult social care services](#).

For the purpose of these recommendations 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. This is reflected in the guideline title 'people growing older with learning disabilities'. Within the recommendations, this long form is used at the beginning of each section but in subsequent recommendations 'people' or 'people with learning disabilities' is used as a short hand. In all cases, the intended population is 'people growing older with learning disabilities'.

## **Glossary**

### **Family members, carers**

(includes people who are related to the person with a learning disability and anyone else who helps to provide informal support, for example friends; it does not cover staff who are paid to provide care or support)

### **Family members and carers**

(includes people who are related to the person with a learning disability and anyone else who helps to provide informal support, for example friends; it does not cover staff who are paid to provide care or support)

### **Lasting power of attorney**

(a legal document that lets someone appoint 1 or more people to make decisions on their behalf, should they be unable to, and that can be made in relation to health and welfare, and property and financial affairs)

## Practitioners

(in these recommendations, '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, which 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)

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(all the people who provide emotional and practical help to a person with a learning disability, which 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)

## Sources

Care and support of people growing older with learning disabilities (2018) NICE guideline NG96

## Your responsibility

### Guidelines

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline

to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

### **Technology appraisals**

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, health professionals are expected to take these recommendations fully into account, alongside the individual needs, preferences and values of their patients. The application of the recommendations in this interactive flowchart is at the discretion of health professionals and their individual patients and do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Commissioners and/or providers have a responsibility to provide the funding required to enable the recommendations to be applied when individual health professionals and their patients wish to use it, in accordance with the NHS Constitution. They should do so in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

### **Medical technologies guidance, diagnostics guidance and interventional procedures guidance**

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, healthcare

professionals are expected to take these recommendations fully into account. However, the interactive flowchart does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

Commissioners and/or providers have a responsibility to implement the recommendations, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations. Nothing in this interactive flowchart should be interpreted in a way that would be inconsistent with compliance with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.