

NICE impact

People with a learning disability



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Insight from Sarah Coleman



Sarah Coleman, health policy officer at Mencap, considers the role of NICE in improving outcomes for people with a learning disability.

“We welcome the commitment from NICE to get it right for people with a learning disability. Both mainstream and specialist learning disability services across both health and social care need guidance, support, training and resources to ensure they can meet the needs of people with a learning disability. For

NICE this means good quality guidance and products for the specialist services, and just as importantly, ensuring that guidance for mainstream services enables them to also care effectively. In addition, NICE has a role to play to ensure services can work together, joining up care so people with a learning disability do not fall through the gaps.

As we rebuild from the pandemic, and redesign our services according to the Long Term Plan and the integration agenda, NICE has a key role to play in making sure that we address those gaps, so health and social care services can deliver the joined up, co-ordinated care that is desperately needed.”

Why focus on people with a learning disability?

Around 950,000 adults and 300,000 children in England have a [learning disability](#). Many people with a learning disability experience poorer health and die at a younger age.



Over 20 years less life

The average age at death for people with a learning disability is 23 years younger for men and 27 years younger for women than the wider population

Source: [Learning disability mortality review](#), 2020



Long hospital stays

57% of people in a mental health hospital with a learning disability, autism, or both have been there for over 2 years

Source: [Health and care of people with learning disabilities, NHS Digital](#), 2021



COVID-19

was the leading cause of death in people with a learning disability for males aged 35 or over and females aged 20 and over in England, in 2020

Source: [Learning disability mortality review](#), 2020

Having a learning disability can affect how a person learns new things throughout their lifetime. A learning disability affects the way a person understands information and how they communicate. This means they can have difficulty understanding new or complex information, learning new skills, or coping independently.

People with learning disabilities have individual strengths and abilities that should be recognised, alongside meeting any identified support needs. They may need a range of extra support throughout life, depending on the complexity of their learning disability.

Care and support services for people with a learning disability should be person-centred, empowering people with a learning disability to make their own choices about what is important to them in their life.



“People with a learning disability like me, want to live good, long lives and achieve our goals. There is so much work still to do to make sure that everyone has the right support. If the guidance puts people with a learning disability first, then the commissioners and services will be able to do the same.”

Brendan Chivasa, Harrow

We have worked in partnership with people who have lived experience of health and social care to produce [a suite of guidance and advice covering the care and support of people with a learning disability](#). This focuses on people growing older with a learning disability, behaviour that challenges and mental health problems. People who have learning disabilities, their families and carers and staff who support them were committee members during guideline production, [and they talk about the experience in this video](#).

All of our guidance is relevant to a person with a learning disability, and we have produced the following specifically on learning disability

4 guidelines **3** quality standards **1** NICE advice product

We recognise throughout the report that the health and social care system is complex and there are many factors that influence changes in practice and outcomes, including increased uptake of NICE guidance. We work with stakeholders and partners in health and social care to support these changes.

The report looks at key themes covered by our guidance, focusing on those highlighted to us by partners and areas where we have uptake data. The data shows high levels of health inequality and limited positive change over time in some areas. The [NHS Long Term Plan](#) sets out actions to tackle the causes of poorer health and preventable deaths. Through increased implementation of our guidance we believe this can improve.

Reducing health inequalities

Health inequalities are unfair and avoidable differences in health across the population and between different groups within society. People with a learning disability are under served in access to healthcare and experience high levels of health inequality. We have set out, across a range of guidance, recommendations that, when implemented, will result in a reduction in health inequalities for people with a learning disability.

The [2020 annual report from the Learning Disabilities Mortality Review \(LeDeR\) programme](#) highlights stark inequalities between people with and without a learning disability. Avoidable medical causes of death include those that are preventable through effective public health and primary prevention interventions, and those that are treatable by timely and effective healthcare interventions.

41% of adult deaths were from treatable medical causes and
24% were from preventable medical causes

Source: [learning disability mortality review](#), 2020

LeDeR reports have shown that, compared with the general population, people with a learning disability were 3 to 4 times as likely to die from an avoidable medical cause of death. Most of the avoidable deaths in people with a learning disability were because timely and effective treatment was not given.

These reports also show that deaths of people with an Asian/Asian British family background were 9 times higher than someone with a white British family background. The overall number of deaths in this group is small, so these findings should be interpreted with caution, but not with complacency. The small number of recorded deaths may be because people with a learning disability from a minority family background are not on their GP's learning disability register or known to services such as the local learning disability team.

A [Public Health England study on COVID-19 in people with a learning disability](#) found that the death rate was 6 times higher for people recorded as having a learning disability than in the general population during the first wave in spring 2020.

Learning disability health checks

Many people with a learning disability have considerable, and often multiple, physical and mental health conditions. People with a learning disability are at increased risk of developing chronic conditions from both genetic factors and lifestyle factors.

In England, rates of heart failure, epilepsy, severe mental illness, stroke and transient ischaemic attack, diabetes and dementia are higher in adults with learning disability than in the wider population, [according to a study by Carey et al. \(2016\)](#).

46% of adults with a learning disability had between 7 and 10 long-term conditions when they died

Source: [learning disability mortality review](#), 2020

Gaps in the understanding of the needs of people with a learning disability, as well as barriers in communication, can mean people with a learning disability have more difficulty getting treatment for health conditions.

To help increase access to healthcare, [our guideline on challenging behaviour and learning disabilities](#) recommends that people with a learning disability should be offered an annual health check. This is built on in our guideline on [mental health problems in people with learning disabilities](#), which sets out how the annual health check should identify physical and mental health problems.



“Health checks have always been good for me, got one tomorrow. The nurse there is good, she speaks slowly and clearly. Checks my understanding. My last health check was last December and they are usually once a year like they should be. I feel listened to when I explain how I have been feeling.”

Person with a learning disability, London

Using [NHS England's learning disability annual health check electronic clinical template](#), GPs should offer an annual health check to all adults with a learning disability, and all children and young people with a learning disability who are not having annual health checks with a paediatrician.

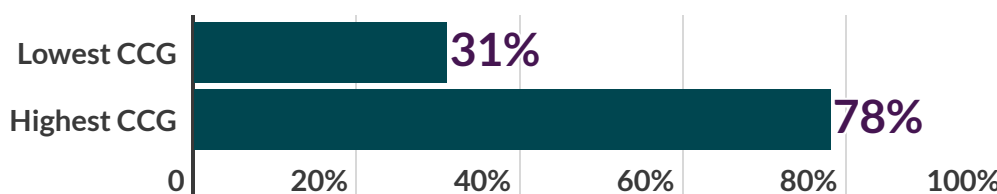
The proportion of eligible people with a learning disability who have had a learning disability health check is increasing

	2015/16	2019/20
Women	52%	58%
Men	51%	57%

Source: [NHS Digital's health and care of people with learning disabilities](#), 2021

[Our quality standard on learning disability: care and support of people growing older](#) states that health checks should be undertaken by an appropriately trained provider and sets out the minimum elements that should be included in health check protocols. Variation between clinical commissioning groups can be seen in the proportion of people with a learning disability who receive an annual learning disability health check. In 2018/2019 this ranged from 31% to 78%.

Variation by clinical commissioning group (CCG) in the proportion of people with a learning disability who have had a learning disability health check



Source: [NHS Digital's health and care of people with learning disabilities](#), 2019 to 2020

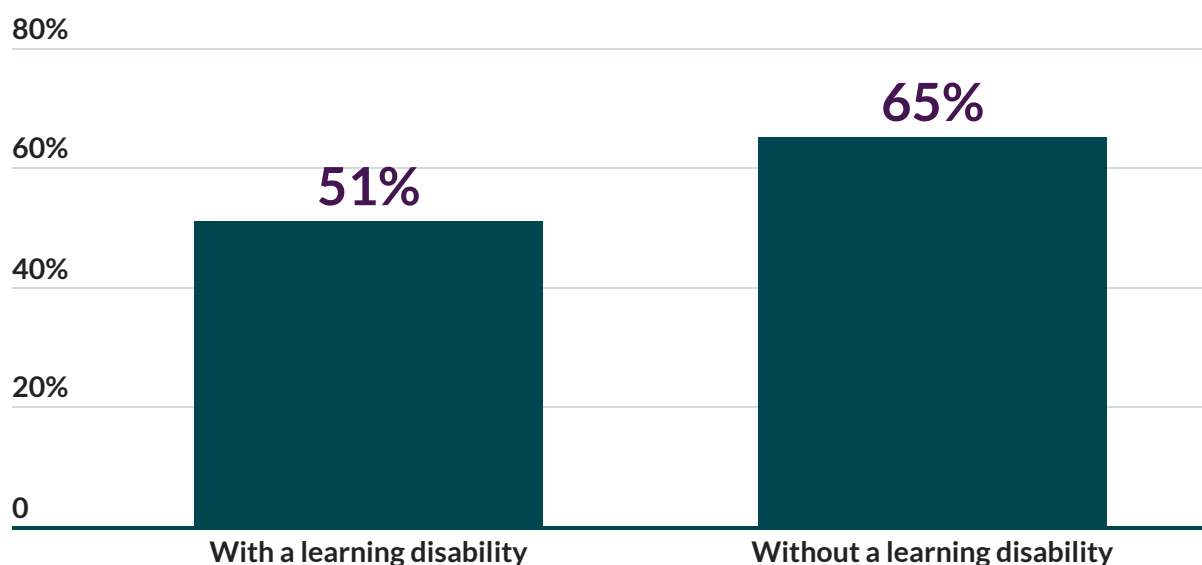
The [NHS Long Term Plan](#) commits to improving access to the existing annual health check in primary care for people with a learning disability aged over 14 years, so that at least 75% of those eligible have a health check each year.

Cancer screening

An important element of learning disability health checks is making sure that routine healthcare, such as cancer screening, has taken place, and offering advice if not. [Our guideline on care and support of people growing older with learning disabilities](#) recommends that older people with a learning disability should be offered the same routine screening and health checks as older people without a learning disability. Health professionals should support people to be aware of and to access services such as breast and bowel cancer screening and smear tests by considering reasonable adjustments. These programmes can lead to earlier diagnosis, enabling earlier treatment and improved outcomes.

In England, breast screening is currently offered to women aged 50 up to their 71st birthday. The [NHS Digital publication health and care of people with learning disabilities 2019 to 2020](#) looks at a sample of English GP practice data covering women aged 50 to 69. It shows that breast screening rates in this sample are lower for people who are recorded as having a learning disability.

The proportion of women aged 50 to 69 who received breast cancer screening in the previous 5 years



Source: [NHS Digital's health and care of people with learning disabilities](#), 2021

Health action plan

In [our guideline on care and support of people growing older with learning disabilities](#) we recommend that any actions identified by the annual health check are recorded in the person's health action plan. The health action plan is a personal plan, developed by the person with a learning disability with their practitioner to stay healthy. This might include support to manage physical or mental health conditions, or actions relating to lifestyle factors, such as diet and exercise. According to [Public Health England's people with learning disabilities report](#), in 2017/18, 88% of practices who provided health checks also recorded health action plans.

Updating the COVID-19 rapid guideline on critical care

At the start of the pandemic, we published a COVID-19 rapid guideline on critical care in adults. After publication, patient groups raised concerns about the application of the guideline recommendations on using the Clinical Frailty Scale (CFS) in people with learning disabilities, autistic people and those with other stable long-term disabilities.

We rapidly updated our recommendations to provide clarity that the use of the CFS would be inappropriate in these populations. Alongside this, the [NHS Specialist Clinical](#)

[Frailty Network](#) updated their advice to outline the limitations of using the CFS.

The CFS should not be used in younger people or people with stable long-term disabilities such as cerebral palsy, learning disabilities or autistic people. An individualised assessment is recommended in all cases where the CFS is not appropriate. We are committed to producing guidance and resources to help improve outcomes and enable people with a learning disability to have long and fulfilling lives.

Insight from Sarah Coleman, Mencap

“We always welcome inclusion in the development of NICE products. We believe good quality guidance, which fully considers, and enables staff to meet, the needs of disabled people is paramount. Early in the pandemic, we believe the rush to develop guidance across the NHS left disabled people at risk. For example, some disabled people were encouraged to not attend hospital should they become unwell, as they would not be considered for critical care due to their support needs. Others experienced issues with access to vital support from a carer in hospital trusts, and/or unsafe discharges.

We fear some people may still be falling through cracks in the system. As we

move through the pandemic and beyond, we hope NICE will now lead the way in ensuring that disabled people’s needs are fully considered in the development of policy and practice.

We hope NICE will support services to take proactive steps to reduce health inequality, for example, by offering an annual health check, which significantly reduce the risk of people with a learning disability dying young, providing vital opportunities for GPs to pick up on changes or anything concerning. Good quality annual health checks include health action plans, helping people manage long-term conditions, and access healthcare over the coming year.”

Helping people to access support and care

When someone has a learning disability, it is important that it is recorded in their health records so that they can receive the care and support they need. [Our guideline on care and support of people growing older with learning disabilities](#) recommends that health and social care commissioners should identify the number of adults in their area with a learning disability and use this information to identify gaps in provision, organise services and plan future provision. We suggest that encouraging GPs to develop and maintain registers of people with a learning disability is one route to achieving this.

However, [Public Health England's people with learning disabilities in England 2015 report](#) suggested that only 25% of the estimated 1.2 million adults and children in England with a learning disability have their disability recorded on their GP's register. This could mean that people with a learning disability are not receiving care such as annual health checks, flu vaccinations or, more recently, coronavirus vaccinations. To help improve this, NHS England has published [guidance for general practice on improving identification of people with a learning disability](#), and organisations such as Mencap have produced [information to help people with a learning disability make sure they are on the register](#).

Reasonable adjustments

Reasonable adjustments are a legal requirement to make sure services are accessible to all people with protected characteristics under the [Equality Act 2010](#). Our guideline on care and support of people growing older with learning disabilities states that service providers and commissioners must make these reasonable adjustments.



“Reception can be difficult. It can be very mixed. Some receptionists are really good and communicate really well but others are not so good. They don't think about the words they are using and make it hard to understand what I need to do.”

Person with a learning disability, London

The amount of support a person with a learning disability needs will depend on the extent of their disability. It can be more difficult for a person with a learning disability to communicate with others or understand, learn and remember new things. [NHS England's reasonable adjustments for accessing health services](#) include providing easy read appointment letters, longer appointments and taking into account sensory concerns.

45% of acute hospital trusts provide accessible appointment letters

Source: [learning disability improvement standards for NHS trusts](#)



“A young man with autism spectrum disorder, ADHD and a learning disability was due to receive his COVID vaccination. The first time it didn't work because no reasonable adjustments were made but the GP, the home, the acute liaison nurse and I worked out a plan together that worked. The GP came to the person's home rather than the surgery, easy read information with clear pictures about what would happen was provided and the person had lots of favourite activities and staff to hand to help distract him.”

Speech and language therapist, learning disability outreach team

NHS England's [learning disability improvement standards for NHS trusts](#) showed that 94% of people with a learning disability said they were treated with respect when using their trust's services. However, only 45% of specialist learning disability services and 37% of acute hospital trusts maintain contact with people with learning disabilities who are waiting to be seen and offer flexible appointments. When trusts were asked if they have mechanisms to identify people with a learning disability, autistic people, or both, 79% could. However, just 23% of acute hospital trusts are able to recognise if someone on a waiting list has a learning disability.

Adjustments may also be required so that people with a learning disability can access work. [Our guidance on mental health problems in people with learning disabilities](#) says adults with a learning disability (with or without mental health issues) interested in accessing paid or unpaid work should be supported.

Reasonable adjustments may be needed to help people engage with, and contribute to communities. [‘Access to Work’ is a publicly funded employment support programme](#) that aims to help more people with a disability start or stay in work. The number of people with a learning disability who received a payment for any ‘Access to Work’ provision has increased, from 1,640 in 2015/16 to 3,560 in 2019/20.

Insight from Sarah Coleman, Mencap

“We know that many people will need support to come forward to get on the learning disability register. Some groups are under represented, including some minority ethnic communities, children and young people, and older people who may not have a formal diagnosis. Accessible information and resources aimed at these groups may help, as may targeted action from primary care services.

In addition to acting as a passport to particular services, recording that

someone has a learning disability can help to ensure that services are aware of the adjustments and support that somebody needs to access healthcare. We are looking forward to the NHS Digital reasonable adjustment flag being introduced by 2023/24 as part of the Long Term Plan. However, we must also recognise the role for training – as without this, despite a ‘flag’ on the system, many staff will still find themselves unable to apply this information to their practice.”

Reducing overmedication and long-term hospital care

Too many people with a learning disability are prescribed medication inappropriately or are kept in long-term hospital care against their best interests.

Reducing overmedication

[Our guideline on challenging behaviour and learning disability](#) says that antipsychotic medication should be considered only in very limited circumstances, and always offered in combination with psychological or other interventions. [Our quality standard on learning disability: behaviour that challenges](#) says antipsychotic medication should be reviewed 12 weeks after starting treatment and then at least every 6 months.

A [Public Health England study on antipsychotic and antidepressant medicines](#) shows widespread prescribing of psychotropic medicines (antipsychotics, antidepressants and hypnotics) for people with a learning disability, many of whom do not have a relevant diagnosis recorded.



30,000 to 35,000

adults with a learning disability in England are taking psychotropic medicines without a relevant diagnosis

Source: [Prescribing of psychotropic medication for people with learning disabilities and autism, Public Health England, 2015](#)

[Prescribing data from NHS Digital's health and care of people with learning disabilities](#) shows the proportion of people with a learning disability prescribed antipsychotics fell by just 1% between 2015/16 and 2019/20. The percentage of patients without a learning disability being prescribed antipsychotics remained steady over the same period.

The NHS Long Term Plan commits to expanding the [stopping over medication of people with a learning disability, autism or both \(STOMP\)](#) and [supporting treatment and appropriate medication in paediatrics \(STAMP\)](#)

programmes to stop people with a learning disability, autistic people, or both being prescribed too much medication. STOMP-STAMP provides support to begin the process of challenging the continued need for psychotropic medication in people with a learning disability, autistic people, or both. NHS England's [learning disability improvement standards for NHS trusts](#) reports that only 62% of services have a clear policy to safeguard people from inappropriate use of psychotropic medication.

The proportion of people with and without a learning disability receiving treatment with antipsychotics

	2015/16	2019/20
With a learning disability	16%	15%
Without a learning disability	1%	1%

Source: [NHS Digital's health and care of people with learning disabilities](#), 2021

Reducing reliance on long-term hospital care

Admission to assessment and treatment units (ATUs) and other mental health hospitals should only take place if assessment and care planning shows that people's needs cannot be met safely in the community and all possibilities for doing so have been considered and exhausted.

The parliamentary Joint Committee on Human Rights report on the [detention of young people with learning disabilities and/or autism in Assessment and Treatment Units \(ATUs\) and other mental health hospitals](#) concluded that young people's human rights are being abused; they are detained unlawfully contrary to their right to liberty, subjected to solitary confinement, more prone to self-harm and abuse and deprived of the right to family life. The [House of Commons Health and Social Care Committee 2021 report on the treatment of autistic people and people with learning disabilities](#) highlighted the lack of adequate community provision, resulting in people remaining in secure institutions where they are unable to live fulfilled lives and are too often subject to treatment that is an affront to a civilised society.

[Our quality standard on learning disability: behaviour that challenges](#) sets out actions to prevent unnecessary inpatient admissions. These include assessment to identify possible triggers and access to specialist behavioural support in the community.

[Our guideline on service user experience in adult mental health](#) recommends that access to mental health services, including crisis support, should be available when needed.

When staying in hospital, [our guideline on learning disabilities and behaviour that challenges](#) recommends that, as soon as the person is admitted, the hospital and community learning disability team should work with the person to develop a discharge plan together. A person's discharge plan should be reviewed at least every 3 months. [Our guideline on transition between inpatient mental health settings and community or care home settings](#) says that links with home community, including relationships, employment and education, should be maintained.

We recommend that local authorities and clinical commissioning groups should jointly designate a lead commissioner to oversee commissioning of health, social care and education services specifically for all children, young people and adults with a learning disability, including those who display, or are at risk of developing, behaviour that challenges. This could be part of [an integrated care system](#). The aim is to simplify the system, make better use of resources and clarify responsibilities. It may improve the experience and outcomes of people with a learning disability by reducing crises and the need for more intensive support.

35% of people in a mental health hospital with a learning disability, autism, or both had been in hospital for over 5 years

Source: [Assuring Transformation Collection, NHS Digital, 2021](#)

[NHS Digital publishes monthly data in the Assuring Transformation Collection](#) about people in a mental health hospital setting with a learning disability, autistic people, or both. A snapshot taken in April 2021 showed that 2,075 people with a learning disability, autistic people, or both were staying in hospital, and around half were on a secure ward. Many had been in hospital for a long time; 1,240 had a total length of stay of over 2 years. These are similar numbers to the April 2020 snapshot.

In collaboration with people with lived experience and a range of stakeholders, including NICE, the British Association of Social Workers has produced [Homes not hospitals, a publication for NHS and local authority commissioners, and social workers](#) to support preventing people with a learning disability, autistic people, or both from being admitted to hospital unnecessarily and to help get those who are currently in assessment and treatment units or restrictive settings home.

The [NHS Long Term Plan](#) includes a focus on the number of people in hospital settings. It aims to reduce the time people spend in hospital and to support earlier transfers of care. By 2024 the number of inpatient beds for people with a learning disability, autistic people, or both will be half of 2015 levels.

[Our guideline on learning disabilities and behaviour that challenges](#) says inpatient services and community learning disability teams think about using [NHS England Care and Treatment Reviews](#) (CTRs) process as a framework for reviews to support discharge in adults. CTRs aim to support people to remain in their community, reduce the number of people being admitted into hospital and to make sure the length of time spent in hospital is no more than necessary. CTRs are for autistic people, people with a learning disability, or both, whose behaviour is seen as challenging. They can also be for people with a mental health condition. [Care, Education and Treatment Reviews](#) are also available for children and young people.

63% of people in a mental health hospital with a learning disability, autism, or both had a care and treatment review in the previous 6 months

Source: [Assuring Transformation Collection, NHS Digital, 2021](#)

[NHS Digital data on CTR](#) shows that 39% of people with a learning disability, autistic people, or both have a preadmission CTR and almost two-thirds of inpatients had a review of their care in the last 6 months.

Following a long stay in hospital, [our guideline on transition between inpatient mental health settings and community or care home settings](#) recommends having a conversation with the person about follow-up support before discharge. Support should be arranged according to the

person's mental and physical health needs. The hospital team should lead communication about discharge planning with the other services that support the person in the community, such as learning disability services.

Insight from Bella Travis, Mencap

Bella Travis, policy manager at Mencap, comments:

“There is variable progress in delivering the commitments to transform care that government, NHS and partners have made since the Winterbourne View abuse scandal in 2011. Repeated targets to reduce inpatient beds and provide the right support in the community have been missed.

Absolutely key to effective change is the development of the right community support – including input from multi-disciplinary community teams, care providers with the right skills and suitable housing – to prevent admission where possible and ensure timely discharge where people are in inpatient units.

Funding is often piecemeal and does not

seem to be based on a comprehensive analysis of the community support/resource needed to achieve the Transforming Care targets.

Without proper resource and attention on our social care system, many people with a learning disability and their families are left vulnerable to crisis and in-patient admissions as well as being left reliant on harmful and unnecessary medications, taking these medications to manage behaviours that so clearly communicate unmet social care needs.

The integration agenda of health and social care opens the door to new ways of working, and real holistic care for people with a learning disability. We hope to see this clearly reflected in NICE products as we move forward.”

Support and future planning

Social care is care and support that is given to support people with day-to-day living and can range from a few hours a week to 24 hours a day. According to [NHS Digital's adult social care activity and finance report](#), around 840,000 adults in England accessed long-term social care support in 2019/20. For 153,000 of these adults, learning disability was the main reason they needed support.

Social care aims to enable people with a learning disability to live their life in the way they choose. Support can be many things, including supporting somebody to develop friendships and relationships, to do meaningful activities and be part of their local community, or it could be help with washing and dressing. Care and support may only be needed for a short time or may be required throughout a person's life.

Most adults with a learning disability who have long-term social care support receive this in a community setting



Source: [Adult Social Care Activity and Finance Report, England 2019-20, NHS Digital](#)

People who access services

We have published a suite of guidance, standards and advice to help support people with a learning disability to live well. [Our guideline on the care and support of people growing older with learning disability](#) aims to support people to access the services they need as they get older. It does not give a specific age range in the recommendations because adults with learning disability often experience age-related difficulties at a younger age than the general population.

Data from [NHS Digital's Personal social services adult social care survey](#) showed that, in 2019/20, adults using learning disability support services had satisfactory experiences of care. Most people (97%) said that support services improve their quality of life and 81% feel as safe as they want. Almost three-quarters (72%) of adults said they are extremely or very satisfied with the care and support they receive.



“I’m always in charge of my choices. Well, as long as things are explained. They’re not always explained.”

Person with a learning disability, London

There is still more that can be done; for example just 41% say they have as much control over their daily life as they want. In [our guidance on care and support of people growing older with learning disabilities](#) we recommend practitioners should enable people with a learning disability to think about what they want from life as they age and should ensure that care and support is tailored to their needs, strengths and preferences.

Think Local Act Personal has developed [making it real, a framework that sets out 6 themes for personalised care and support](#). Each theme has a number of ‘I’ statements that describe what good looks like for an individual. These are followed by ‘We’ statements that express what organisations could be doing to make sure people’s actual experience of care and support services are personalised.

Future planning

It is important to consider wider needs including housing and opportunities for social interaction. Two-thirds of adults with learning disabilities live with their families, usually their parents, according to [Mencap's Housing for people with a learning disability](#). Eventually, ageing family carers may reluctantly explore alternative care arrangements when they are no longer able to provide long-term care. The death or serious illness of a parent may result in unplanned or multiple moves in accommodation for people with a learning disability.

Thinking about the future is an important aspect of person-centred planning. [Our guideline on care and support of people growing older with learning disabilities](#) recommends practitioners should have person-centred conversations with people growing older with learning disabilities to address their changing needs, wishes and capabilities and promote their independence. The guideline also recommends that practitioners build on the person's strengths and skills and consider how to meet their changing needs and preferences to promote independence. This should include empowering people to build and maintain relationships to reduce isolation. We have produced a [person-centred future planning quick guide](#) for practitioners supporting people growing older with learning disabilities.

Insight from James Robinson, Mencap

James Robinson, policy and strategic lead at Mencap, comments:

“Care and support for people with a learning disability is variable and, after the devastating impact of COVID-19, these variations have become even more stark. Mencap found 7 in 10 people with a learning disability had their care reduced during the first lockdown, which was mostly not reinstated later in the year. This is likely to see an increase in more complex needs further down the line. Funding is needed to both restore access to support for those who had it reduced and to increase support for those whose needs have increased because of the pandemic.

Local authority commissioners should adopt an outcomes-based approach to commissioning, with a focus on early intervention and prevention, to avoid people reaching crisis point. This could

see eligibility criteria reduced to ensure needs are met earlier.

Mencap's own research found that, overall, 26% of local authorities were spending less on social care for people with a learning disability in 2018/19 than they were in 2014/15 despite the fact that the number of people with a learning disability has increased by 30% in a decade. Many local authorities are experiencing efficiency saving and have seen care providers go bust. This has impacted working age disabled adults who have seen their independence, choice and control reduced. Support should be given to people with a learning disability, their families and carers to be actively involved in helping to plan and design services in their local area. Local authorities should be supported to develop the necessary data and feedback to understand local needs now and into the future.”

What is NICE doing next?

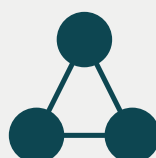
We engaged with external stakeholders to identify implementation challenges and available support across the social and health care system while developing this report. These included:

- NHS England and NHS Improvement
- The Care Quality Commission
- Skills for Care
- The British Association of Social Workers
- The Learning Disability Professional Senate
- Foundation for People with Learning Disabilities
- National Development Team for Inclusion
- The Royal College of Nursing

Stakeholders identified the following as key priority areas:



The uptake and quality of annual health checks



Integrated local commissioning of health, social care and education services



Reasonable adjustments and accessible communication



Health and social care workforce development



Providing personalised care and supporting people to live independent lives in the community

To encourage implementation of our guidance and help the wider system address these priority areas, we will:

- Support NHS England and NHS Improvement in their work to:
 - Develop a Health Improvement Framework
 - Deliver reasonable adjustments in healthcare, such as a reasonable adjustments digital flag in health records
 - Implement recommendations from the [Lives and deaths of people with a learning disability review](#)
- Include learning disabilities in our ongoing work on health inequalities as part of our [new strategy for 2021 to 2026](#). For example, we are working with a NICE fellow to develop a pathway for a successful learning disability annual health check.
- Work with the British Association of Social Workers, Skills for Care and the Care Quality Commission to develop a series of webinars about supporting good lives for people with learning disabilities and autistic adults, including commissioning, good therapeutic care and community and home-based support.
- Engage with social care provider networks, Principal Social Worker Networks and regional Association of Director of Adult Social Services branches to advise on the use of relevant NICE guidance.

Our partners are also doing work in these areas, which is underpinned by NICE guidance. For example:

- Health Education England and Skills for Care are co-ordinating the development of the Oliver McGowan Mandatory Training in learning disability and autism for all health and social care staff, which includes tiers 1 and 2 of the [core capabilities framework](#).
- The Care Quality Commission continue to regulate providers and encourage them to develop services in alignment with national policy, including NICE guidance. They recently published [Right support, right care, right culture](#), which gives guidance to services that provide regulated care to people with a learning disability or autistic people.

We would like to thank Sarah Coleman, Bella Travis and James Robinson from Mencap for their contributions to this report. We would also like to thank all individuals and organisations who took the time to talk to us and provide input into this report.

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Any enquiries regarding this publication should be made to:

National Institute for Health
and Care Excellence
Level 1A, City Tower
Piccadilly Plaza
Manchester
M1 4BT

Telephone: +44 (0)300 323 0140

Email: impact@nice.org.uk

Website: nice.org.uk

