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# Tackling inequalities in care for people with learning disabilities and autistic people

A guide for adult social care professionals

January 2025





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## About SCIE

The Social Care Institute for Excellence improves the lives of people of all ages by co-producing, sharing, and supporting the use of the best available knowledge and evidence about what works in practice. We are an independent social care charity working with organisations that support adults, families and children across the UK. We also work closely with related services such as health care and housing.

We improve the quality of care and support services for adults and children by:

- identifying and sharing knowledge about what works and what's new
- supporting people who plan, commission, deliver and use services to put that knowledge into practice
- informing, influencing and inspiring the direction of future practice and policy.

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## Summary

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### Context

In the UK, a learning disability is defined by the Department of Health and Social Care (DHSC) (2001) as: “a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood.”

A learning disability is different for everyone. The degree of disability can vary greatly, being classified as mild, moderate, severe or profound. In all cases, a learning disability is a lifelong condition and cannot be cured.

A learning disability is different to a learning difficulty, which is a reduced ability for a specific form of learning and includes conditions such as dyslexia (reading), dyspraxia (affecting physical co-ordination) and attention deficit hyperactivity disorder (ADHD). A person with a learning disability may also have one or more learning difficulties ([Gov UK, 2023](#)).

Additionally, there are a number of conditions and neurological disorders that often involve or cause some type of learning disability, including Down’s syndrome, autism, meningitis, epilepsy or cerebral palsy.

“A learning disability is not a physical disability” ([Gov UK, 2023](#))

People with learning disabilities continue to experience poor health outcomes in comparison to the rest of the general population, leading to lower life expectancy and a higher number of avoidable deaths (42% compared to 22% of the general population) ([House of Commons Committee Report, 2024](#)).

According to data from the Local Government Association (LGA) and the Association of Directors of Adult Services (ADASS) around 1.04 million people aged 15 to 64 in England have learning disabilities or autism ([LGA, 2024](#)).

This group experience disproportionate levels of inequality and their quality-of-life outcomes are lower than it is reasonable to expected in the 21st century. Prior to COVID-19, ([Heslop, 2014](#)) revealed a lack of awareness, understanding and skills amongst the health and social care workforce about the health risks facing people with learning disabilities, and how to ensure that that they receive the right care.

### Background

SCIE’s ‘[Tackling inequalities in care for people with learning disabilities and autistic people](#)’ project explored the inequalities faced by people living with learning disabilities and autistic people, such as delays in diagnosis, lack of reasonable adjustments, and ‘diagnostic overshadowing’.

SCIE worked with ‘[The SCIE Fliers](#)’ a co-production group of people with learning disabilities and autistic people, to understand people’s experiences of the COVID-19 pandemic to draw

out lessons and opportunities for learning that could be shared to support the sector and ultimately support improvements in care and support. This led to the development of the ‘**Am I invisible**’ materials which feature on the SCIE website.

During this project, SCIE worked alongside people with learning disabilities and autistic people to understand their experiences and views on what needs to be different. SCIE also facilitated a series of events with different sector partners, to showcase the work developed by the co-production group, and develop the conversation further.

This guidance document brings together learning from our discussions and work with commissioners, service providers and people with learning disabilities. We recognise that some of the challenges that people with learning disabilities and autistic people experienced during and after the pandemic are not new. Many of those challenges were prevalent before the COVID-19 pandemic, an example of this is the winter pressures on the wider system.

We aim to create an understanding of the inequalities and the areas that health and social care services can act upon to address them, and to close the gap in skills and knowledge in the health and social care workforce.

This guidance is not exhaustive and builds on the tools available across the health and social care sector to support people with learning disabilities and autistic people. While reference has been made to specific documents throughout, feedback from people with learning disabilities and autistic people has been paramount in developing this guidance.

## Who will benefit from this guidance?

- Commissioners and providers of health and social care services for people with learning disabilities and autistic people.
- Practitioners from the health and social care sector working with people with learning disabilities and autistic people.
- Practitioners and providers working with people with learning disabilities and autistic people in wider settings, including education, housing, the voluntary and community sector, employment and criminal justice services.

## What will you gain from this guidance?

- The knowledge of practical steps you can take to improve experiences of care for people with learning disabilities and autistic people.
- Increased confidence in the delivery and commissioning of services for people with learning disabilities and autistic people.
- Awareness of the legislative and legal frameworks that underpin practice for those working with people with a learning disability and autistic people.

## Legislative framework

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The legislations listed below apply to services for people with learning disabilities and autistic people. Service providers and local authorities have a responsibility to provide services within this framework. People with learning disabilities and autistic people in the UK are protected under the below legislative framework which the government and relevant authorities are under obligation to abide by:

- **Mental Health Act 1983**
- **Mental Capacity Act 2005**
- **Equality Act 2010**
- **Data Protection Act 2018**
- **Health and Care Act 2022**
- **Human Rights Act 1998**
- **Care Act 2014**
- **Social Services and Well-being (Wales) Act 2014**
- **Health and Social Care (Safety and Quality) Act 2015**
- **Autism Act 2009**
- **Down Syndrome Act 2022**

### Mental Health Act 1983

The **Mental Health Act 1983** is the legislation that applies to people's rights regarding pathways into hospital, assessment and treatment across England and Wales.

Many people being treated in hospitals that provide inpatient mental health care, psychiatric wards or in a specialist mental health service are there by their own free will. They have the right to refuse treatment should they wish. This is called being a 'voluntary' or 'informal patient'.

However, if a person needs urgent treatment for a mental health disorder and are at risk of harm to themselves or others then they may be detained or admitted without giving consent into hospital or a secure unit for assessment or further treatment. People admitted in this way are referred to as 'formal patients'.

Whilst detained, several of one's rights are taken away from them, such as their freedom to leave the facility and in some cases their right to refuse treatment.

Some people meeting the conditions to be detained under the Act have experienced inappropriate care, a lack of specialised services tailored to their needs, overuse of restraints, over-medication, and extended periods of detention.

As of March 2024, 2,045 people with a learning disability or autistic people were in hospital in England:

- 32% were diagnosed with a learning disability.
- 48% were diagnosed with autism.
- 20% were diagnosed with both a learning disability and autism.

Of these, 91% were detained under the Mental Health Act, and 9% were informal patients ([UK Parliament, 2024](#)).

After an independent review of the Act in 2018, the Government introduced a draft Mental Health Bill in 2022 to modernise the Act and reduce detentions. During the [King's Speech](#) in 2024 it was announced that the [Mental Health Bill](#) will deliver on the commitment “to modernise the Mental Health Act 1983 which is woefully out of date”.

The Mental Health Bill will amend the Mental Health Act 1983 to give people detained greater choice and autonomy, enhanced rights and support, and ensure everyone is treated with dignity and respect throughout treatment by:

- ensuring that detention and treatment under the Mental Health Act takes place only when necessary
- further limiting the extent to which people with a learning disability and/or autistic people can be detained and treated
- strengthening the voice of patients
- strengthening and improving the statutory roles
- removing police stations and prisons as places of safety under the Mental Health Act
- supporting offenders with severe mental health problems to access the care they need.

For further information and guidance on the Mental Health Act 1983 please see:

- [Mind](#)
- [NHS guidance](#)

## Mental Capacity Act 2005

The [Mental Capacity Act \(MCA\) 2005](#) is designed to protect and restore power to those vulnerable people who may lack capacity to make certain decisions, due to the way their mind is affected by illness or disability, or the effects of drugs or alcohol.

The MCA applies to everyone working in social care, health and other sectors, who is involved in the support and treatment of people aged 16 and over, who live in England and Wales, and are unable to make all or some decisions for themselves.

The MCA has five key principles:

- **Principle 1 – a presumption of capacity:** this means that you cannot assume that an a person with a learning disability or an autistic person is unable to make a decision for themselves because they have a particular medical condition or disability.
- **Principle 2 – individuals must be supported to make their own decisions:** sometimes people with learning disabilities and autistic people may need extra support to communicate their understanding of a situation or decision but must always be encouraged to make the decision for themselves.
- **Principle 3 – unwise decisions:** we all have our own values, beliefs and preferences. Just because someone wants to make a choice that others may deem 'unwise', doesn't mean that they don't have the capacity to make that decision.
- **Principle 4 – best interests:** if a decision is made on behalf of a person with learning disabilities or an autistic person because they don't have the capacity to make the decision themselves, then the decision must be made in the best interests of that individual.
- **Principle 5 – least restrictive option:** if someone is making a decision on behalf of a person with learning disabilities or an autistic person then they must consider whether it is possible to decide or act in a way that would interfere less with the person's rights, freedom of action, or whether they need to decide/act at all.

It is important to remember that capacity is decision and time-specific.

For more information about the MCA 2005 please visit the [SCIE website](#).

## Equality Act 2010

It is the [Equality Act 2010](#) that outlines the key concepts of equality, prohibited conduct, and the responsibilities of employers, statutory services and premises to prevent inequality.

The Act prevents an individual from being discriminated against the following nine protected characteristics:

- age
- disability
- gender reassignment
- marriage and civil partnership
- pregnancy and maternity
- race
- religion or belief
- sex



- sexual orientation.

The Act defines that a person has a disability as if they live with a physical or mental impairment, and the impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities ([Equality Act 2010](#)).

People with learning disabilities and autistic people may need some extra support or reasonable adjustments to fully engage with a working environment, participate in services, access the community, or live a wholesome life.

If additional required support is not put in place, then that person may be facing discrimination.

## Data Protection Act 2018

People with learning disabilities and autistic people may receive services from private and statutory organisations, requiring various levels of information about the person to be captured and used to tailor support.

The [Data Protection Act 2018](#) and the contained General Data Protection Regulations (GDPR) provide explicit directions on how organisations should handle, store and process personal data.

It is important to be constantly mindful to embed the [seven key principles of the GDPR](#) across all of your practice:

- lawfulness, fairness and transparency
- purpose limitation
- data minimisation
- accuracy
- storage limitation
- integrity and confidentiality (security)
- accountability.

## The Health and Care Act 2022

Since the introduction of the [Health and Care Act 2022](#), we saw the collaboration of local NHS organisations, local authorities and third sector partners into 42 Integrated Care Systems (ICS) where there is a more coordinated approach to planning and commissioning across each of the regions.

This means that people with learning disabilities and autistic people can benefit from a more locally tailored approach to meet their needs.

## Care Act 2014

The **Care Act 2014** is the most significant piece of legislation in our sector and shifts the emphasis of local authorities from a duty to provide services to meeting eligible needs.

The introduction of the Act meant that the person is put at the centre of what local authorities can offer and to have a conversation about what that means for the individual, maximising their involvement in processes and decisions.

The Act focuses on preventing and delaying the progression of needs and is resulting in the investment of preventative services and community resources or assets.

The Act establishes a national minimum threshold at which people have eligible needs or will be eligible for care and support.

Once an assessment and eligibility process is complete, there's a duty on local authorities to produce care and support plans by directly involving the person, and to offer a personal budget if the person has eligible needs.

Many people with learning disabilities and autistic people will be eligible for services and support through the criteria of the Act.

For young people with special educational needs (SEN) who have an Education, Health and Care (EHC) plan under the Children and Families Act 2014, preparation for adulthood must begin from year 9 - see **Special Educational Needs & Disability (SEND) Code of Practice 'Preparing for Adulthood'**. The transition assessment should be undertaken as part of one of the annual statutory reviews of the EHC plan and should inform a plan for the transition from children's to adult care and support.

SCIE continues to work closely with central and local government to produce useful resources that will enable local authorities to further improve social care practice, in alignment with legislative requirements and good practice.

A range of videos and resources on the Care Act 2014 can be found on the **SCIE website**.

## Social Services and Well-being (Wales) Act 2014

The **Social Services and Well-being (Wales) Act 2014** is the legislation "that provides the legal framework for improving the well-being of people who need care and support, and carers who need support, and for transforming social services in Wales" (**Social Care Wales, 2024**). Its emphasis on wellbeing reflects a holistic approach beyond someone's basic health needs and the understanding that wellbeing is personalised to the individual.

According to the **National Framework for Commissioning of Care and Support in Wales** the Act seeks to transform social care in Wales so that it achieves two principal objectives of having services that achieve the wellbeing of citizens, "what matters" to them as they define it; having services that are sustainable despite demographic trends.

Commissioning should be underpinned by the core values of the Social Services and Well-Being (Wales) Act: voice and control, prevention and early intervention, wellbeing, co-production and multi-agency.

More people are entitled to Direct Payments – receiving money – if they choose to make their own arrangements for the care and support they are assessed as needing. There will be greater transparency when a person is being charged for care, residential or not, and will be provided with a written statement detailing the charge and how it was calculated.

Under Section 145 of the Act, local authorities must act in accordance with the [Codes of Practice](#) and their requirements when exercising their social services functions, this includes assessments, meeting individual's needs and advocacy.

## Human Rights Act 1998

In recent years, a number of initiatives and strategies have been introduced by the government that have prioritised improving the lives of people with learning disabilities and autistic people through better support, services and advocacy.

For instance, human rights are at the very core of person-centred planning, which aims to give people with learning disabilities and autistic people the right to be treated and live life with the same rights, choices and opportunities as everybody else. The [Human Rights Act 1998](#) ensures that people with learning disabilities are not discriminated against. It is important that professionals apply the principles of this Act as a tool for advocacy to protect the rights and dignity of people with learning disabilities and autistic people.

## Health and Social Care (Safety and Quality) Act 2015

The intention of the [Health and Social Care \(Safety and Quality\) Act 2015](#) is to reduce the harm in care by imposing requirements that services providing regulated activities “cause no avoidable harm to the person for whom the services are provided”.

Each nation has its own standards of care and regulatory bodies to ensure providers maintain a level of quality and safety for people receiving support through care services provided by statutory, private or voluntary organisations.

Below are useful links for each nation:

### England

- [Care Standards Act 2000](#)
- [Care Quality Commission](#)
- [Social Work England](#).

### Northern Ireland

- [Care Standards](#)
- [The Regulation and Quality Improvement Authority \(RQIA\)](#)

- **Northern Ireland Social Care Council (NISCC).**

## Scotland

- **National Care Standards**
- **The Care Inspectorate**
- **Scottish Social Services Council (SSSC).**

## Wales

- **Health and Care Quality Standards**
- **Care Inspectorate Wales**
- **Social Care Wales.**

## Autism Act 2009

The **Autism Act (2009)** aims to address the multiple social disadvantages and health and care inequalities autistic adults face by creating a **strategy and guidance** for local authorities, NHS bodies and Foundation Trusts to ensure a greater awareness of autism, better assessment of support needs and provision of support.

In 2019 the All Party Parliamentary Group on Autism (APPGA) produced a report, '**The Autism Act, 10 years on**', that explained that although polling from the National Autistic Society suggested that 99.5% of people have heard of autism, only 24% of autistic adults and 26% of family members told the APPGA inquiry they thought public understanding of autism had improved since the Autism Act was passed.

The current strategy, '**The national strategy for autistic children, young people and adults: 2021 to 2026**', provides a roadmap of activity to demonstrate the transformation of autistic people and their families' lives by:

- Improving understanding and acceptance of autism within society
- Improving autistic children and young people's access to education and supporting positive transitions into adulthood
- Supporting more autistic people into employment
- Tackling health and care inequalities for autistic people
- Building the right support in the community and supporting people in inpatient care
- Improving support within the criminal and youth justice systems.

## Down Syndrome Act 2022

The **Down Syndrome Act 2022** is a short piece of legislation that aims to improve access to services and to improve the quality of life for people with Down syndrome. It requires the Secretary of State to provide guidance to a range of public bodies in the NHS, social care, housing, and education and youth offending, on how to meet the needs of people with Down syndrome.

The enactment of the legislation was followed by a call for evidence seeking input from people with lived experience, their families and carers, and professionals to contribute to the content of the guidance.

A **statement from the DHSC** in March 2024 announced the formal commencement of “the Down Syndrome Act 2022 by way of regulations, which bring into force all the provisions of the Act and is a necessary step towards the publication of guidance”. As of the release of this publication, the draft of statutory guidance is still pending release for public consultation.

For further information see: **[The Down Syndrome Act](#)**

## Delivering services

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Services and professionals within health and care have an important part to play in addressing the inequalities in care and high levels of unmet health needs experienced by people with learning disabilities and autistic people.

The co-production work highlighted the importance in ensuring that any programme of activities offered by different services is meaningful and designed to reduce social isolation and contribute to positive social, physical and mental wellbeing.

Trusted relationships between statutory health care providers, day services, and voluntary and community sector-led groups are vital to address inequalities affecting wider determinants of health, and supporting frontline delivery. These relationships help with sharing resources effectively, facilitate holistic support, tailor services to individual needs and maximise cross-sector collaboration.

Relationships between partnering organisations can be further strengthened by clarifying the expectations of what they hope to achieve from working together by agreeing to a Memorandum of Understanding (MoU). Joint Working Protocols (JWP) can also be developed to clarify working arrangements to help organisations work together to achieve their aims. In some cases, organisations may also need to develop Information Sharing Agreements (ISA) to ensure the safe sharing of sensitive data between organisations to better deliver a service (CQC, 2023).

“The challenges around social care is about adapting to the individual person’s needs. The one thing that I would say has been difficult, is loneliness, is being cut off from my support system, but also my routine and structure.”

**Danny French (Advocate for people with learning disabilities and autism, London borough of Havering) The SCIE Fliers co-production group.**

## Strengths-based approaches

Strengths-based (or asset-based) approaches focus on individuals’ strengths (including personal strengths and social and community networks) and not on their deficits. Strengths-based practice is holistic and multidisciplinary, working with the individual to promote their wellbeing. It is outcomes led and not services led.

The Care Act 2014 requires local authorities to specifically “consider the person’s own strengths and capabilities, and what support might be available from their wider support network or within the community” (SCIE, 2024).

Strengths-based ways of working can only be achieved through partnership working and collaboration with a wider range of statutory partners and other organisations. This ensures that there is strong commitment to strengths-based ways of working across the local place,

and that people are supported to access a broad range of community-based resources, are not impeded by bureaucracy, or bounced from one person to the next.

Strengths-based models shift the focus from what people with learning disabilities and autistic people cannot do to what they can do with the right support.

The aim should be to involve people, families, and carers in solutions that respond to the individuals' strengths and needs, recognising that people with disabilities have the potential to progress.

A framework has been set out by [LGA](#) to support people with learning disabilities and autistic people to have better lives. The aim of the framework is to help directors of adult social services work with their colleagues and partners to identify how they can improve the way everyone supports people with learning disabilities and autistic people and how they can be assured that the care and support in their area is high quality and strengths-based.

"People with autism needs a quiet space in doctor surgeries. Too much noise, I don't like the overload."

**Sedley Wilson (Chairman of Croydon People First. London Borough of Croydon) The SCIE Fliers co-production group.**

## Person-centred care and support

Starting with the ethos that everyone is unique and has immense potential, our role as professionals is to help people discover their innate skills, find out what they want from their lives, and provide support to help individuals in reaching their life goals.

Practitioners should put time and resources into understanding the person they are supporting, their family circumstances, find out the support needs of their carers, and develop a holistic support plan.

Professionals must actively involve people with a learning disability and autistic people in all decisions that they are affected by involving family members, friends, carers or independent advocates if this is what the person wants. If the person is aged 16 or over and lacks the capacity to make a decision, professionals must follow the [Mental Capacity Act 2005](#).

Listening and empathy skills are crucial to supporting people with learning disabilities and autistic people.

The key principle should be that each person's needs are looked at on an individual basis and preferences must be taken account of individually.

Blanket policies do not help as they can be restrictive due to the individual differences of people's medical condition, disability, or age. As advised by NHS England guidance this is particularly important regarding 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) orders, which should only ever be made on an individual basis and in consultation with the individual and/or their family.



The **LeDeR Annual Report (learning from lives and deaths: People with a learning disability and autistic people)** considered the circumstances of 3,648 people with a learning disability and autistic people who died.

They reported that “reviewers identified that for 16.1% of deaths that occurred in 2022 where a DNACPR recommendation was in place and a conversation about DNACPR was held, the person with a learning disability was not engaged in the discussion about DNACPR where they had capacity. Reviewers were unable to report whether a conversation took place for a further 33.1% of cases”.

It found that when care packages met a person’s needs and there is an appropriate use of Deprivation of Liberty Safeguards to deliver care, then there was an associated reduced risk of a premature death.

It found that while there is progress, “things may not be improving fast enough, and overall care and outcomes for people with Learning Disabilities all too often still fall below acceptable standards compared to the general population”.

### Trauma-informed care

“Trauma-informed practice is an approach to health and care interventions which is grounded in the understanding that trauma exposure can impact an individual’s neurological, biological, psychological, and social development. It aims to recognise the signs, symptoms, and widespread impact of trauma, and to prevent re-traumatisation.” (**Office for Health Improvement & Disparities, 2022**).

Delivering care to people with learning disabilities and autistic people requires sensitivity to the impact of trauma that they may have experienced. Professionals may struggle to translate the principles of a trauma-informed approach into everyday practice.

Professionals at all levels require access to resources, relevant and accessible training in trauma-informed practice and support to ensure a trauma-informed service delivery.

Useful trauma-informed care **resources and references** for practitioners.

“Some carers was rude to me, some carers didn’t know how to talk to me, some carers shouting to me as well. The other thing I don’t like is when the carers call last minute, calling sick, and the agency sends me a new carer. So then I have to explain to them all over again, what to do, step by step.

And a person with a speech impediment, it’s not easy to explain to them what to do.”

**Jaspaul Vilkuh (Campaigns and Advice Project Officer, Speak Out in Hounslow)**  
**The SCIE Fliers co-production group.**



## Hospital passport

A hospital passport helps people with learning disabilities and other lifelong disabilities, and autistic people, give hospital staff important information about their preferences for support and communication, and their health when they go to hospital.

People with learning disabilities and autistic people, and their families, have shared that a hospital passport has significantly improved communication between patients and hospital professionals and are regarded as accessible to use. This also helps with achieving the right level of care and keeping people with learning disabilities safe.

A hospital passport is a document about the person and their health and support needs. It also has other useful information, such as the person's interests, likes, dislikes, how the person may communicate and any reasonable adjustments they might need. If a person is being referred to a hospital by their doctor, the hospital may have specialist learning disability nurses who are available to support the person and ensure they receive good care.

The nurse can meet with the person and their carer before or when they go to hospital to find out as much as possible to understand the help they may need while in hospital. It might be useful for professionals to ask people with learning disabilities if they hold a hospital passport and if they can share the document with people involved in their care with appropriate permissions ([NHS, 2022](#)).

## Support for carers and family members

As stated in the Care Act, carers and family members should be active partners in care and support processes, of which assessment is one (the others being support planning and review). This is because carers and family members are seen under the Act as best placed to judge and make decisions about their own wellbeing.

The involvement of the carer in any assessment about people with a learning disability and autistic people is therefore of paramount importance under the Care Act. The local authority **should** ensure their involvement is maximised and that carers remain central to the process and any decisions made about, or will affect, the person they care for. As well as the wellbeing of people with learning disabilities and autistic people, the wellbeing of carers is equally important and should be considered holistically when planning support ([SCIE, 2022](#)).

## Equality, diversity and inclusion

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Although the topic of equality, diversity and inclusion was not discussed with the SCIE fliers it is important to understand the impact the Equality Act 2010 has on people with learning disabilities and autistic people, and how this is reflected statistically.

### Working population

According to the [Office for National Statistics \(ONS\)](#) across the year 2021, “disabled people with severe or specific learning difficulties (26.2%), and autism (29.0%) had employment rates that were lower than disabled people with other impairment types”.

### Housing

From the [Census 2021](#), the ONS reported that people’s housing situation did not differ significantly between most impairment types. However, those with autism, or severe or specific learning difficulties were more likely than those with any other main impairment type to be living with parents (76.0% and 65.9% respectively). They were also less likely to own their own homes compared with any other main impairment type (3.8% and 8.0% respectively).

### Wellbeing

Although the ONS did not report the results of wellbeing specifically of people with learning disabilities and autistic people and they found that:

“On average, disabled people aged 16 to 64 years had poorer ratings than non-disabled people on all four personal well-being measures, with the greatest disparity in average anxiety levels. The mean scores on these measures were:

- life satisfaction: 6.5 out of 10 for disabled people, compared with 7.6 for non-disabled people.
- for feeling that the things done in life are worthwhile: 7.0 out of 10 for disabled people, compared with 7.9 for non-disabled people.
- for happiness yesterday: 6.4 out of 10 for disabled people, compared with 7.6 for non-disabled people.
- for anxiety yesterday: 4.6 out of 10 for disabled people, compared with 3.0 for non-disabled people (higher numbers equate to poorer well-being in this measure).”

In addition they found that “disabled people were more likely to report feelings of loneliness ‘often or always’ (15.1%) than non-disabled people (3.6%)”. The disparity between disabled and non-disabled people has risen by 7.4 percentage points compared with 2014 (10.9% disabled and 3.5% non-disabled).

## Mortality

The [LeDeR Annual Report \(learning from lives and deaths: People with a learning disability and autistic people\)](#) found that “people from all ethnic minority groups died at a younger age in comparison to people of white ethnicity, when adjusting for sex, region of England, deprivation, place of death, and type of accommodation”.

The percentage-increased risk of dying for ethnic minority groups compared to white ethnicity backgrounds is shown below:

- +81% Mixed ethnicity
- +150% Asian or Asian British
- +168% Other ethnicity
- +190% Black, black British, Caribbean, or African.

## Lesbian, gay, bisexual, transgender, queer or questioning, or another diverse gender identity (LGBTQ+)

The Autism Research Centre conducted a study on the sexual health, orientation, and activity of autistic adolescents and adults ([Weir et al., 2021](#)) and found that autistic adults and adolescents are approximately eight times more likely to identify as asexual and ‘other’ sexuality than their non-autistic peers.

In addition, a study on the elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals found “that transgender and gender-diverse adult individuals were between three and six times more likely to indicate that they were diagnosed as autistic compared to cisgender individuals” ([Warrier et al., 2020](#)).

One of the researchers, Simon Baron Cohen states “Both autistic individuals and transgender and gender-diverse individuals are marginalized and experience multiple vulnerabilities. It is important that we safe-guard the rights of these individuals to be themselves, receive the requisite support, and enjoy equality and celebration of their differences, free of societal stigma or discrimination” ([University of Cambridge](#)).

Mencap indicates that “LGBTQ people with a learning disability face ‘double discrimination’ because of their sexuality or gender (Snell, 2018)” ([Mencap, 2024](#)).

## Co-production

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The Care Act's statutory guidance defines Co-Production as "...when an individual influences the support and services received, or when groups of people get together to influence the way that services are designed, commissioned and delivered" ([Gov UK, 2024](#)).

However, co-production also promotes an equal partnership between people who draw on care and professionals ([SCIE, 2022](#)).

The benefits include:

- The use of people's experience and expertise, which can contribute to a more efficient use of resources.
- An increased sense of social responsibility and citizenship and benefits to the wider community, particularly to improved health and wellbeing.

Professionals collaborating with communities and people who draw on care and support are likely to have a stronger focus on the outcomes of the support provided when they are co-producing, and potentially a greater focus on prevention. So, there are improved outcomes for people who draw on care and support as a result.

The contribution that co-production makes to developing social networks and communities is another benefit. It has been argued that this only happens where there is collective co-production with groups and communities and not where co-production is confined to individuals being involved in the services they receive ([SCIE, 2022](#)).

For further information and examples on good practice examples including case studies and scenarios of co-production in social care and beyond please see the [SCIE website](#).

The SCIE project 'Tackling inequalities in care for people with learning disabilities and autistic people' involved working with a co-production group, the 'SCIE Fliers', reflecting on their COVID-19 pandemic experiences.

They generated a set of critical lessons and suggestions for improvements at systemic and practice level. Such as:

- Look at different ways of hearing directly from the people you work with, so that you can provide the kinds of services that will carry out their views and wishes.
- As we move towards more 'hybrid working', using a mixture of communication methods try to find a good balance between meeting with people face-to-face (which they usually prefer) as well as making contact by phone and online.
- Involve people directly in making decisions about their care, benefits and rights.
- Recognise the roles of an individual's informal carers and advocates, especially regarding capacity issues.

Further information can be found on the SCIE website: [Am I Invisible? Using co-production to advocate change in social care](#).

As part of sharing this co-production work a SCIE workshop event focused on sharing the themes and findings from this work.

One of the key learnings from the SCIE workshop has been the need to focus on both co-production and groups that are already on the radar, along with finding new ones. Individuals also found that the feedback loop approach ‘you said, we did’ worked well. This meant that people felt listened to and their voices mattered and that they could influence change.

Professionals should work in partnership with, and communicate, in ways and means that are accessible and in safe places taking a joined-up approach, from charity groups to GP surgeries to hospitals, from libraries to bus stops, using videos and posters.

### Emergent themes from the co-production group and wider stakeholders

Through the co-production work there was a list of prevalent themes. They include:

- morbidity
- access to services
- diagnosis
- training
- health problems
- health promotion
- health checks
- services for people with learning disability from black and minority ethnic populations.

Inequalities are found in all of these areas, and the reasons and causes can be complex and multifaceted. However consistent areas included:

- limited resources
- professional prejudice
- inadequate responses to characteristics shown by people with learning disabilities and autistic people.

While existing services may work for some individuals, we know they are not always accessible or appropriate for other individuals. This guidance highlights a summary of the measures needed to address this.

“Sometimes it takes me longer to get the council to listen. When I used to work with the learning disability, the commissioning team, then I could get someone listening straight away, but since that person’s left it’s harder to get someone to listen to what people need.”

**Sedley Wilson (Chairman of Croydon People First, London Borough of Croydon) The SCIE Fliers co-production group.**

## Training and development

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As part of the tackling inequalities project **SCIE co-produced a film** with people with learning disabilities and autistic people. A group of experienced London-based self-advocates met to discuss their own stories from the COVID-19 pandemic. The group felt that staff need further training from people with learning disabilities and autistic people, so that they do their jobs better for all, especially older and disabled people (**SCIE, 2023**).

As highlighted in the film professionals should consider:

- Changing needs (including health), wishes and capabilities.
- Encouraging and supporting independence.
- Activities and any practical support needed to access services, including transport.
- How people could build and maintain support networks.
- Information and support needs of family members (including siblings) and carers.
- Carer's assessments.
- Creating a future plan.

**“Disability Awareness Training can and should be delivered by people with learning disabilities and autism” – “Am I Invisible” Using co-production to advocate change in social care (SCIE, 2023)**

## Commissioning checklist

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Feedback from people with lived experience, commissioners and providers is crucial to drawing up the service delivery specification.

The total expenditure of adult social care in England increased by £2.7 billion in real terms from 2010/11 to 2022/23 ([The Kings Fund, 2024](#)). There was also a significant shift from spending on nursing and residential care settings to supported accommodation and community-based services.

With the change in commissioning emphasis and increase of real expenditure, commissioning and procurement processes should consider:

- legal duty
- baseline data
- quality and integration
- unmet needs
- personalisation
- community assets and community first
- outcomes
- cost of living
- workforce retention, training and development
- **levelling-up** community care.

## Conclusion

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To summarise, people with learning disabilities and autistic people have complex health issues, many differing from those of the general population.

- There is a difference between learning disabilities and learning difficulties, and everyone's experience is different.
- Good social care identifies the needs faced by people with learning disabilities and autistic people and offers support within the legislative framework to improve their quality of life, access to health care, and to prevent suffering, morbidity, and furthering inequality.
- Strengths-based models shift the focus from what people with learning disabilities and autistic people cannot do to what they can do with the right support.
- The key principle to person-centred care is that each person's needs are looked at on an individual basis and preferences must be taken account of individually.
- The benefits of co-production impact the system, organisations, practitioners, and people accessing services.
- The wider system across health and social care should be supported with specific training in strengths-based approaches and partnership working, which may make an important contribution in enhancing future accessibility of primary health and social care services for people with learning disabilities and autistic people.

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