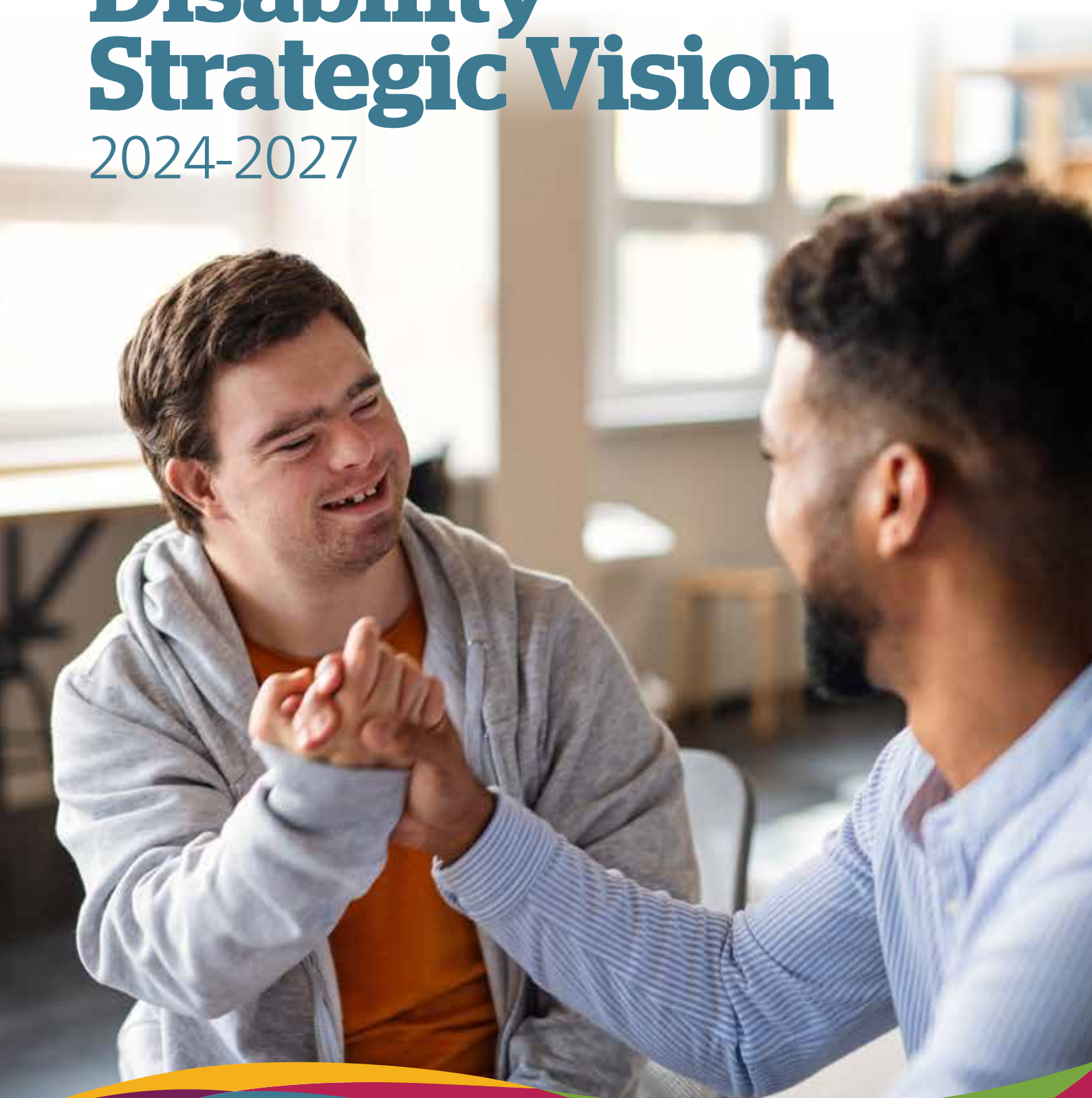


# Learning Disability Strategic Vision

2024-2027



**PROUD TO  
MAKE A DIFFERENCE**

SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST





***“Listening, taking time to understand people’s needs and communicating with them in a way they can engage with can all help people feel like partners in their care”.***

‘Experiences of being in hospital for people with a learning disability and autistic people’ CQC 2022





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# Why learning disabilities matter to us

Sheffield Teaching Hospitals NHS Foundation Trust (STH) is committed to ensuring that our services are fully accessible and that they meet the diverse needs of the people we serve. We also aim to positively promote inclusivity and ensure our treatment pathways are always personalised and meet individual patient needs.

This document sets out STH's ambition and standards for compassionate, person centred care for people with a learning disability. Patients with a learning disability should be able to expect high quality and safe care when they use our services. The NHS Long Term Plan has pledged to improve services for people with a learning disability and reduce inequalities in care and outcomes for this group of people and we have aligned our plans locally.

This includes having a three-year strategic vision for improving care and experience for people with a learning disability when they attend our services whether that be as an inpatient, outpatient in the community or as a family member or visitor. Our Learning Disability Strategy Group developed the vision building on the views of stakeholders, people with learning disabilities, their families and carers and their experiences of using our services.

The 3 priority areas of Co-production, Reasonable Adjustments, and Support describe how STH aims to provide quality healthcare to service users with a learning disability. Read more about these priorities on page 11.



# What is a learning disability?

Learning disabilities affect approximately 1.5 million people in the UK and are common lifelong conditions. Mencap describes a learning disability as “a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life”<sup>1</sup>

Learning disability is divided into four classification groups: mild, moderate, severe and profound. The diagnosis of a profound and multiple learning disability is used when the individual has more than one impairment (i.e. sensory, physical, complex health needs, mental health issues). People with profound and multiple learning disabilities will require support from a carer(s) to assist them with most areas of everyday life, such as eating/drinking, washing/dressing and going to the toilet.

## Supporting families and carers

The impact of supporting a person with a learning disability in accessing healthcare on families and carers cannot be underestimated. It is critical to the healthcare and wellbeing of all concerned that families and carers are carefully considered and supported. STH recognises the exemplary care and support that families and carers provide when supporting people with learning disabilities to access the Trust and value their views on where we can make things better.

***“It is difficult to say my symptoms. I am happy that mum can speak for me.”***

Patient Feedback 2023

<sup>1</sup> <https://www.mencap.org.uk/learning-disability-explained/what-learning-disability>

<sup>2</sup> Barroso, N. E., Mendez, L., Graziano, P. A., & Bagner, D. M. (2018). Parenting stress through the lens of different clinical groups: A systematic review & meta-analysis. *Journal of Abnormal Child Psychology*, 46, 449–461

<sup>3</sup> Iacono, T., Bigby, C., Unsworth, C., Douglas, J., & Fitzpatrick, P. (2014). A systematic review of hospital experiences of people with intellectual disability. *BMC health services research*, 14(1), 1-8.

# Policy context

Thanks to the Six Lives Report<sup>4</sup> and Death by Indifference<sup>5</sup> there have been significant national policy and legislative developments over recent years recognising the importance of improvements in health and social care for individuals with learning disabilities.

<sup>6</sup>Annual LeDeR (Learning from Lives and Deaths) reviews have also supported in-depth learning regarding healthcare for people with learning disabilities. The Sheffield annual LeDeR report (2021)<sup>6</sup> identified care in 42% of reviewed cases as unsatisfactory which was an increase on 2016-2020 when 32% of care in reviewed cases was identified as unsatisfactory.

Following the findings from the Transforming Care Report,<sup>7</sup> which recommended stronger action in improving healthcare for people with learning disabilities, the publication of the Learning Disability Improvement Standards for NHS Trusts<sup>8</sup> was welcomed. This vision was developed with a focus on human rights, taking into account the Human Rights Act<sup>9</sup> and the Care Quality Commission human rights-based framework.<sup>10</sup> A focus of the subsequent NHS Long Term Plan<sup>11</sup> is that the NHS will do more to ensure that all people with a learning disability, autism, or both can live happier, healthier, longer lives and that all care commissioned by the NHS will need to meet the Learning Disability Improvement Standards. Aspects of the NHS Long Term Plan which were particularly relevant to healthcare for people with learning disabilities in an acute Trust included:

- Reduction of health inequalities affecting people with learning disabilities
- Implementing reasonable adjustments to support equality of access.
- Increasing awareness of the needs of people with learning disabilities and collaborating with them and their families

The STH Learning Disability Strategic Vision was written in accordance with three universal standards from the Learning Disability Improvement Standards for NHS Trusts:

1. Respecting and protecting rights – using reasonable adjustments, learning from deaths, promotion of anti-discrimination.
2. Inclusion and engagement – engage with people receiving care their families and carers, co-design services, empower people with learning disabilities to exercise their rights.
3. Workforce – staff with specialist knowledge and skills, workforce plans to manage and mitigate shortages of qualified practitioners.

<sup>4</sup> Parliamentary and Health Service Ombudsman 2008-09 Six lives: the provision of public services to people with learning disabilities

<sup>5</sup> White, A., Sheehan, R., Ding, J., Roberts, C., Magill, N., Keagan-Bull, R., ... & Strydom, A. (2022). Learning from Lives and Deaths-People with a learning disability and autistic people (LeDeR) report for 2021.

<sup>7</sup> Transforming Care for People with Learning Disabilities – Next Steps, 2015

<sup>8</sup> Improvement, N. H. S. (2018). The learning disability improvement standards for NHS trusts. NHS Improvement, London.

<sup>9</sup> Human Rights Act 1998 <https://www.legislation.gov.uk/ukpga/1998/42>

<sup>10</sup> Care Quality Commission (2014) Human rights approach for our regulation of health and social services

<sup>11</sup> NHS Long Term Plan 2019 <https://www.longtermplan.nhs.uk/>

# Sheffield context

STH employs approximately 19,000 staff and provides integrated hospital and community-based healthcare. This care is provided largely for residents of Sheffield, South and Mid Yorkshire, North Derbyshire and, for some specialist services, residents across England. This care is provided at multiple sites across Sheffield and provides over 2 million patient contacts each year.<sup>12</sup>

Sheffield is one of the 20% most deprived authorities in England and rates of individuals living in deprivation are higher in people with learning disabilities compared to the wider population,<sup>13</sup> which has a direct impact on access to healthcare<sup>14</sup>.

Data from the Quality and Outcomes Framework estimate that there are almost 4,500 people with learning disabilities known to be living in Sheffield.<sup>16</sup> However, as there are many people with learning disabilities who are not known to services, this figure is estimated to be somewhere in the region of 12,500 people with learning disabilities living in Sheffield. It is also recognised that these figures are expected to grow as people live longer and healthcare services get better at recognising learning disabilities. While estimates vary, the number of people with profound and multiple learning disabilities is reported to increase annually by 1.1%.<sup>17</sup>

Life expectancy for people with learning disabilities is significantly less than the wider population. However, it has been rising in recent years.

One of the reasons for the poorer health outcomes for people with learning disabilities are inequalities<sup>20</sup> which have been carefully considered in the Sheffield Joint Health & Wellbeing Strategy<sup>21</sup> and the city-wide health strategy for people with learning disabilities.<sup>22</sup> The STH Learning Disability Strategic Vision focuses on delivery of acute care and the specific barriers encountered by recipients of healthcare provided by STH and aligns with the wider STH Corporate Strategy - Making a Difference, The Next Chapter.<sup>23</sup> For context and recognising the wider considerations of the Learning Disability Community. The vision considers the needs of patients with both Learning Disabilities and Autism. Recognising that the needs of our Autistic Community are different to those of the Learning Disability Community, the STH Learning Disability Strategy Group are developing an Autism Strategic Vision.

<sup>12</sup> Sheffield Teaching Hospitals Making a Difference The Next Chapter 2022-27 <https://www.sth.nhs.uk/clientfiles/File/Making%20a%20difference%20-%20the%20next%20chapter%202022-27%20copy.pdf>

<sup>13</sup> Emerson E. Poverty and people with intellectual disabilities. *Mental retardation and developmental disabilities research reviews*. 2007;13(2):107-13

<sup>14</sup> Peters DH, Garg A, Bloom G, Walker DG, Brieger WR, Hafizur Rahman M. Poverty and access to health care in developing countries. *Annals of the new York Academy of Sciences*. 2008;1136(1):161-71

<sup>15</sup> <https://fingertips.phe.org.uk/profile/learning-disabilities>

<sup>16</sup> Sheffield's Learning Disabilities Strategy 2023-2030, [https://www.sheffield.gov.uk/sites/default/files/2024-01/appendix-3-what-we-know-about-learning-disabilities-in-sheffield-v1.2%2022.12.23.pdf](https://www.sheffield.gov.uk/sites/default/files/2024-01/appendix-3-what-we-know-about-learning-disabilities-in-sheffield-v1.2%202022.12.23.pdf)

<sup>17</sup> Emerson, E. (2009). Estimating future numbers of adults with profound multiple learning disabilities in England. *Tizard Learning Disability Review*, 14(4), 49-55.

<sup>18</sup> White, A., Sheehan, R., Ding, J., Roberts, C., Magill, N., Keagan-Bull, R., ... & Strydom, A. (2022). Learning from Lives and Deaths-People with a learning disability and autistic people (LeDeR) report for 2021.

<sup>19</sup> <https://www.sheffielddccc.nhs.uk/Downloads/Our%20strategy/MHLDA/Sheffield%20LeDeR%20Report%202020-21%20vF.pdf>

<sup>20</sup> Emerson, E. (2021). Inequalities and inequities in the health of people with intellectual disabilities. In *Oxford Research Encyclopaedia of Global Public Health*.

<sup>21</sup> Sheffield Joint Health & Wellbeing Strategy 2019-2024, <https://democracy.sheffield.gov.uk/documents/s34751/Join%20Health%20Wellbeing%20Strategy%202019-24.pdf>

<sup>22</sup> Hear Our Voice, Sheffield's Learning Disability Strategy 2023-2030 <https://www.sheffield.gov.uk/disability-mental-health/learning-disability-strategy>

<sup>23</sup> Sheffield Teaching Hospitals NHS Foundation Trust Making a Difference, The Next Chapter 2022-2027 <https://www.sth.nhs.uk/futureplans>





## What matters to you?

At STH our goal is to provide holistic care in partnership with our patients. As part of this ongoing commitment and in developing our approach to patient centred care for patients with Learning Disabilities, we engaged with our patients and asked, 'what matters to you?'

Through engagement with our stakeholders, it was discovered that some people using the Trust were not confident that they would always receive the reasonable adjustments that they required.

A further key theme identified by the engagement exercise was the use of accessible information. The Trust has an Accessible Information Standard (AIS) group which is developing ways of increasing the use of accessible information across the Trust, such as ensuring the Trust's new electronic patient record meets AIS requirements, completion of an AIS compliance benchmarking exercise and the roll-out of an AIS training package.

Participants in the engagement exercise highlighted environmental factors as a barrier to access to healthcare, such as high levels of noise. STH has completed extensive work on improving environmental surroundings such as some quieter rooms in the Emergency department at the Northern General Hospital.

Carer involvement continues to be a concern for people with learning disabilities, their families and carers. In response to the Adult Health and Social Care Carers Delivery Plan,<sup>25</sup> STH has published and publicised its Carers and Young Carers Policy. This is supported by e-learning available to all staff.



# Where are we now?

A Care Quality Commission (CQC) inspection and report of STH in 2022 recognised that whilst we are a supportive and inclusive organisation, further work in improving the healthcare for adults with learning disabilities at the Trust was required.<sup>24</sup> In addition to these reports, the Sheffield Teaching Hospitals Engagement Network carried out a project to seek and review feedback from people with learning disabilities, their families, and their carers about their experiences of using STH services.

Since 2022 lots of progress has been made towards reaching goals for improvement with many projects still ongoing.

# Where do we want to be?

Through our engagement with key stakeholders where we asked, “What matters to you?” It was discovered that people with learning disabilities have a mixed experience using services provided by the Trust. As part of our plans the Trust want to provide consistently good care across our sites by engaging with training opportunities as they become available, raising awareness of the importance of this training with the STH workforce.

We also want to coordinate care in a seamless way for patients who require a multidisciplinary approach to reduce the stress that more complex care can provoke. Our excellent relationships with other sectors gives us the opportunity to reduce silo working and develop a co-ordinated approach.

It is essential that we have a comprehensive understanding of our population of people with learning disabilities who access the Trust to facilitate appropriate care and pro-active planning of robust services. This includes more comprehensive incident reporting and learning, greater use of relevant digital systems and embedding a truly co-productive approach to future policies and action plans affecting the healthcare of people with learning disabilities, their families and carers.

<sup>24</sup> Sheffield Teaching Hospitals NHS Foundation Trust - Care Quality Commission [Internet]. [cited 2024 Jan 7]. Available from: <https://www.cqc.org.uk/provider/RHQ/inspection-summary>

## What recent changes have been made?

In the Sheffield LeDer report from 2021, STH committed to increased use of health passports. Audits were subsequently completed which identified some staff and people with learning disabilities were unaware of health passports, lack of support to complete or read them, and underuse of passports when they were available.

STH have a Learning Disability and Autism Team, which was set up in March 2023. The team provides a liaison service, training, and support to staff. In a relatively short time this team has already demonstrated a significant impact on the healthcare experience of people with learning disabilities who access the Trust. The training that this team have provided to date has included use of the Health Passport and provision of reasonable adjustments. The number of Learning Disability Champions is increasing across the Trust. Champions work closely with the liaison team and support better care for patients.

With regards to health outcomes STH continues to engage with the LeDeR Quality Assurance Group to understand and act on findings regarding specific areas of treatment and care. Uptake of the annual health check in parts of Sheffield is higher than the national average. There remains a need however, to understand the completeness of these health checks and whether they result in appropriate numbers of referrals to acute care.

There are multiple resources to support staff including but not limited to the Mental Capacity Trust Sharepoint, Mental Capacity training, the Mental Health Strategy, Mental Health Resource Sharepoint, Mental Health Training.

# Our strategic priorities and ambitions for change

Three priorities have been identified which have the greatest potential to improve the healthcare for people with learning disabilities at STH. These are:

## Coproduction

Embed Coproduction, and Collaboration into decision-making and healthcare planning

## Reasonable Adjustments

Ensure Reasonable Adjustments are available and used

## Support

Support staff to provide the best care for people with learning disabilities

## Coproduction

We know how important it is to work and engage with people with learning disabilities along with their carers and family members to understand how our services feel from their perspective. Patient engagement allows us to check how services are being experienced currently and how we could do better. We take learning from many different avenues including listening to patient voice groups, feedback from complaints and holding regular reviews.

### What good looks like:

- People with learning disabilities, their families and carers report that they are listened to, and their recommendations are acted upon where possible.

### Ambitions for Change:

- Continue to identify key areas in the Trust where development is most needed by collaboration with users of Trust services, their families and carers on a regular, ongoing basis.
- Develop the scope of the STH Ask, Listen, Do Group to support developments within individual departments.
- Ensure co-production in the design and implementation of STH action plans for care for people with learning disabilities.



# Reasonable Adjustments

STH are committed to providing a responsive service which recognises the needs of patients who may be disadvantaged in accessing care and treatment due to disability or other health inequalities and providing reasonable adjustments to support them.

The Equality Act 2010 (incorporating the Disability Discrimination Act 2005) puts the responsibility on all public services to ensure that no discriminatory practices exist within their organisation, that services meet the needs of the individual and reasonable adjustments are made.

## What good looks like:

- Application of reasonable adjustments is consistent across the Trust
- Healthcare provision is agile and people with learning disabilities, their families and carers have choices on healthcare delivery where this is possible
- STH has a comprehensive picture of the use of Trust services by people with learning disabilities
- People with learning disabilities can communicate with the Trust in an accessible way

## Ambitions for Change:

- Streamline clinical pathways affecting people with learning disabilities.
- Embed how policies and procedures are applied when providing care for people with learning disabilities across Trust-wide policies
- Expand the range of essential materials related to the care of patients with Learning Disability
- Support the use of reasonable adjustments across the Trust.
- Nurture accessibility by supporting different environments such as outreach provision for patients with learning disabilities
- Improve contact and communication with the Trust by increased easy read information, video, text, email and communication tools.
- Increase use of health passports and make available in multiple formats.
- Enable and empower carers to support the people they are caring for when accessing healthcare.
- Build on developments in healthcare transition to support young people and their carers when moving to adult services.

***“I would never have managed to have the surgery if the staff hadn’t put these things in place”***

*“The staff did everything possible to help make his stay comfortable and not stressful, they allowed me to be with him every step of the way, which help him. Staff was very accepting”*

Carer Feedback 2023

## Support

The NHSE Learning Disabilities Standards Benchmarking report<sup>28</sup> notes “Trusts must ensure staff have the specialist knowledge and skills to meet the unique needs of people with learning disabilities, autism or both who access and use their services, as well as those who support them.”

Identification of key areas in the Trust where development is most needed will be gathered by collaboration with users of Trust services, their families and carers. Staff are also well placed to identify some of the barriers specific to the departments in which they work. The beneficial impact of specialist staff for people with learning disabilities is well documented<sup>29</sup> and the understanding and knowledge of specialist Trust staff will be gathered to gain insight on how to provide the appropriate support across different departments.

### What good looks like:

- Staff feel empowered and confident in their capacity to provide high quality healthcare for people with learning disabilities
- Staff have a range of resources and support available to them when providing care for people with learning disabilities

### Ambitions for Change:

- Increase training on the topic of care for individuals with learning disabilities for staff
- Deliver bespoke training to STH researchers in research involving participants with learning disabilities
- Understand specific barriers that staff experience in improving care for people with learning disabilities
- Improve recognition of problems with accessing Trust services for people with learning disabilities

<sup>28</sup> NHS England and NHS Improvement. Performance against the learning disability improvement standards Findings from the benchmarking exercise. (2019). [https://www.england.nhs.uk/wp-content/uploads/2020/08/Learning\\_disabilities\\_standards\\_benchmarking\\_report\\_FINAL.pdf](https://www.england.nhs.uk/wp-content/uploads/2020/08/Learning_disabilities_standards_benchmarking_report_FINAL.pdf)

<sup>29</sup> MacArthur, J., Brown, M., McKechnie, A., Mack, S., Hayes, M., & Fletcher, J. (2015). Making reasonable and achievable adjustments: the contributions of learning disability liaison nurses in 'getting it right' for people with learning disabilities receiving general hospitals care. *Journal of Advanced Nursing*, 71(7), 1552-1563.



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