Learning from lives and deaths - People with a learning disability and autistic people (LeDeR)

Action from learning report 2022/23

Contents

Acknowledgements	3
Foreword	3
What is LeDeR?	7
What you will find in this report	8
New LeDeR resource bank	8
Co-production and family involvement	9
Jack's Story	10
Removing barriers by working together	12
Management of medical conditions in 2022/23	13
- Supporting people with COVID-19 Vaccination Uptake	13
- Respiratory conditions	16
- Dysphagia	18
- Seasonal flu vaccination	20
- Identifying and managing deterioration in health	21
- Constipation	24
- Cancer	25
- Epilepsy	32
Action from learning in 2022/23: changing how we work	36
- Integrated care systems (ICSs) in action	36
- Improving standards across all NHS services within priority groups	37
- Annual health checks (AHCs)	39
- Race, Religion, Ethnicity and Culture	43
- End of life care and advance care planning	48
- Mental Capacity	52
- Reasonable adjustments	53
- Social prescribing and personal health budgets (PHBs)	60
- STOMP and STAMP (medication)	63
New Initiatives	65
Terms and acronyms used	70
APPENDICES	74
Appendix 1: LeDeR Independent Advisory Group Members	74
Appendix 2: Update on actions by NHS England	75
Appendix 3: Case studies by region 2022/23	82
Appendix 4: Integrated Care Systems	86

An easy read version of this report and an accessible film are also available.

The NHS cannot be held responsible for the content of external websites.

Acknowledgements

This LeDeR action from learning report includes examples of the vital work underway across the NHS and by our partners, working with self-advocates and self-advocacy groups, parents/carers, the charity and voluntary sectors, and our colleagues in social care. None of these efforts would be possible without family members, health and social care staff and many others contributing to a LeDeR review by sharing their experience of the life and death of a loved one or someone in their care. We would like to express our sincere gratitude to you all.

We highly value our Independent Advisory Group whose members include people with a learning disability, autistic people, parents and carers, and representatives from the charity and voluntary sectors. They inform and enrich our work. We would like to recognise and thank everyone whose work, campaigning or self-advocacy continues to inform, challenge, change and reduce health inequalities among people with a learning disability and autistic people.

Foreword

Tom Cahill

National Director for Learning Disability and Autism

NHS England

As National Director for Learning Disability and Autism I know how it is important for the NHS to get it right for people with a learning disability, autistic people, and their families. However, the findings of the LeDeR Annual Report state that, despite improvements on previous years, in 2022/23 42% of all the reported deaths of people with a learning disability were avoidable, that is they were caused by conditions that can be mainly avoided through effective prevention or treatment. We remain committed to changing this and will continue to work with staff across the NHS and in the adult social care sector to reduce premature mortality and change and improve outcomes for people with a learning disability.

In the last 18 months there have been significant changes in the NHS to drive improvements to services including services for people with a learning disability and autistic people. Integrated Care Systems (ICSs) in England are now fully operational and are joining up health and care services to improve lives locally. I have visited a number of regions to see how they are addressing LeDeR findings in their new local systems and have been impressed by what I have seen.

The NHS has also published a new strategy to address healthcare inequalities at national and system levels. I am pleased to see the inclusion of Learning Disability in one of the ‘plus’ categories in this strategy. This is important because it helps us make sure that the health of people with a learning disability is everybody’s business across the NHS.

Good training and support for health and care staff is also crucial in reducing health inequalities. The Oliver McGowan Mandatory Training in learning disability and autism is rolling out across England as all regulated service providers must now ensure their staff receive learning disability and autism training appropriate to their role. Learning from LeDeR reviews features in this training.

Annual health checks also play an important role in reducing health inequalities and premature mortality. I am pleased that Primary Care Networks are now provided with 'committed funding' for preventing and tackling health inequalities when they complete a health action plan following an annual health check. This will help us to build on our performance in 2021/22 when 78.1% of people on the GP learning disability register received an annual health check. Primary Care Networks (PCNs) are now also required to record their patient's ethnicity at these checks. This will help to focus attention on the importance of preventing the additional inequalities sometimes faced by people from minority ethnic groups.

This Action from Learning report includes examples of national and local initiatives underway across the NHS to make healthcare better for people with a learning disability, as a result of learning from LeDeR reviews in 2022/23. For example, national guidance on aspiration pneumonia and community acquired pneumonia has been developed to improve the care of people with a learning disability who are at risk of pneumonia and a national constipation campaign is raising awareness of the risks that constipation can pose. Work in West Yorkshire saw people with a learning disability prioritised for surgery when tackling a backlog in elective care whilst the 'decision support tool for physical health' is being used in Cheshire and Wirral, Sussex and other areas to help health system staff identify people with a learning disability who are at risk of premature mortality. Read this report to find out more about these improvements and how you can implement them in your areas.

We are committed to working together and to learn from each other to make a difference, prevent premature mortality and improve the health and lives of people with a learning disability and autistic people.

Foreword

Anne Worrall-Davies

Interim national clinical director, learning disability and autism programme

NHS England

As the Interim National Clinical Director for Learning Disability and Autism, reducing health inequalities is my top priority and I will take every opportunity I can to raise the profile of the LeDeR findings and this Action from Learning Report across the wider NHS health and care system.

I am also personally motivated in this role. As the parent of a son who has a learning disability and epilepsy, I understand first-hand how important it is that the NHS gets it right for people, including my son, to access high quality healthcare – in all settings.

There are so many inspirational examples of good practice in this year's report. I am seeing local systems really deliver against the findings of their LeDeR reviews. Preventative measures are the bedrock of improvements to people's health. Improving access to healthcare through reasonable adjustments, using the legal mandate of the Equality Act, is crucial if we are truly going to address the equality gap between the general population and autistic people and people with a learning disability. Many of the examples in this report – improved access to immunisations against flu and COVID-19 to cancer screening – illustrate how this can be done.

I hope that reading about how they made a difference will encourage everyone working in health and care to continue to improve local services for people with a learning disability and autistic people.

Foreword

Carl Shaw

Learning disability and autism advisor

NHS England

My name is Carl Shaw. I am a person who has a mild learning disability. I work in the LeDeR team at NHS England and provide insight into the needs of people with a learning disability and autistic people.

These are important pieces of work that we are doing to address the health inequalities of people with a learning disability and autistic people:

Firstly I'd like to mention the Race and Health Observatory report[1] that LeDeR commissioned. The fact that I found most shocking was that some people with a learning disability from minority ethnic groups died many years younger than the general population. The [median] age of death for these groups of people[2] is 34 which I find quite worrying because I am white British and am 38 years old so if I wasn't white British I would possibly not be alive today! There are lots of suggestions from the report that NHS staff and other people can act on1.

I have been involved with the LeDeR work to promote annual health checks for people with a learning disability who are on their GP's learning disability register. I have learnt that it is really important to look after my health and live in a healthy way. In 2022 I was invited to attend my annual health check. I was told that I was overweight and my blood sugar was in a pre-diabetic state. I have a good understanding of what foods are healthy for me and the benefits of exercise so I started to change the way I live my life.

One year on in 2023 at this year's health check I was told that my blood sugar levels had returned to normal and I'd lost weight. Knowing that diabetes is a common condition for people with a learning disability, I knew I needed to do something about it. LeDeR is helping to encourage everyone with a learning disability to attend their health check and making sure that there are reasonable adjustments if they need them when they go. This will help to prevent diabetes and other health problems which could be picked up early. I want to make sure that everyone with a learning disability and autistic people get the care and treatment they need to stay healthy and live for a long time, just like everybody else.

[1] More details on the findings in this report are in this report, below and here: https://www.nhsrho.org/wp-content/uploads/2023/07/RHO-Executive-Summary-LD-Report.pdf

[2] Please see 'We deserve better: Ethnic minorities with a learning disability and access to healthcare' for an explanation of the median age at death for people from ethnic minority groups. These findings should be interpreted with caution due to the small number of people who were from ethnic minority groups compared to those denoted as 'white'. https://www.nhsrho.org/wp-content/uploads/2023/07/RHO-Executive-Summary-LD-Report.pdf

I also want to mention a very helpful website called the LeDeR resource bank. It is a place where you can find lots of important information about the main health conditions that people with a learning disability and autistic people experience and what reasonable adjustments you can make to help people. You can find information about cancer, diabetes, and much more.

What is LeDeR?

Learning from lives and deaths - people with a learning disability and autistic people (LeDeR) is a service improvement programme funded by NHS England to help make services better for people with a learning disability and autistic people.

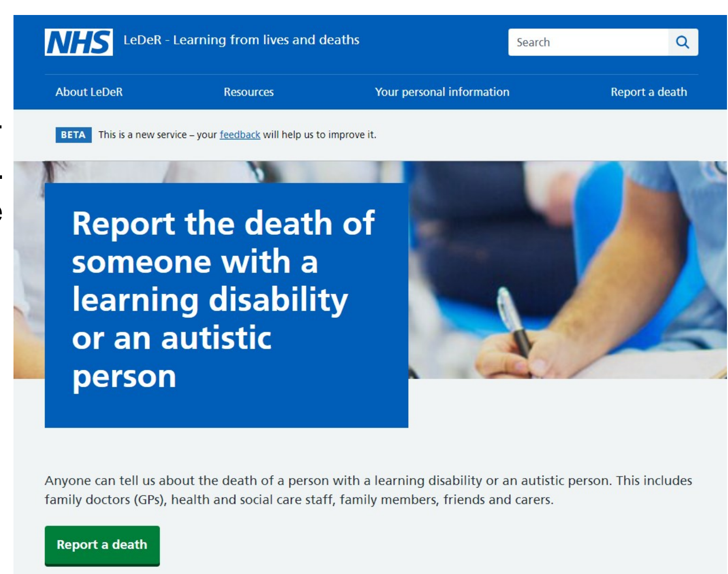
LeDeR shows that people with a learning disability and autistic people die earlier on average than other people, and do not always receive the same quality of care.

When a person with a learning disability or autism dies[3], a 'LeDeR review' looks at the health and social care they received to see where care could have been better and identify examples of good practice.

The insights from these reviews also shed light on specific health inequalities faced by autistic people who do not have a learning disability. We share these insights across England to improve services by learning from one another, to narrow the inequalities people experience in care and to help prevent people dying sooner than they should.

The NHS works to implement what we learn from LeDeR reviews in our local systems, by improving our treatment pathways and ensuring the voices of people with a learning disability and their families and carers are at the heart of our work.

Anyone can notify LeDeR about the death of an adult (aged 18 and over) with a learning disability or with a clinical diagnosis of autism[4] – via the LeDeR website. This includes GPs, health and social care staff, family members, friends and carers. The more deaths that are reviewed and the more information we have about people's lives and care, the more likely we are to be able to improve services for people who have a learning disability and autistic people.



[3] Since January 2022 LeDeR also reviews the lives and deaths of autistic people – including those who do not have a learning disability.

[4] The diagnosis must be recorded in the person's clinical record.

What you will find in this report

This LeDeR action from learning report gives examples of some of the local and national actions across health and social care services to reduce health inequalities for people with a learning disability and autistic people. It includes responses to learning from LeDeR reviews and from previous LeDeR Annual Reports. (Produced by King's College London and others since June 2021 and previously by The University of Bristol). It also provides updates on the commitments we made in our last Action from Learning report. An easy read version and accessible film about this document are available.

New LeDeR resource bank

We have developed a new online LeDeR Resource Bank for health and care staff which includes resources on tackling health inequalities and resources on conditions including cancer, cardiovascular health, dementia, diabetes, end of life care, constipation, epilepsy and respiratory and identifying deterioration. These include links to guidance, training, easy read materials, films and reports.

The NHS is not responsible for the content of external websites.

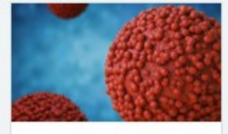
LeDeR Resource Bank

This resource bank may be of use to health and care professionals supporting people with a learning disability or people who are autistic with their health or care.

Around 50% of deaths of people with a learning disability are avoidable. The NHS and our partners are working hard to change this. The categories below include resources to address some of the main causes of early death for people with a learning disability.

Please note the NHS is not responsible for the content of external sites and guidance may be updated.

If you have any comments about the resource bank, or you have a resource that you would like to suggest, please complete the feedback form.


Cancer

Cardiovascular health

Diabetes

End of Life Care

Epilepsy

Identifying Deterioration

Respiratory

Dementia

General resources

Co-production and family involvement

Working with people with lived experience and in partnership with other organisations is central to our work. Our national NHS England team employs people with a learning disability, autistic people, family carers and bereaved family carers to ensure that every aspect of our work is directly informed by their insight.

An independent advisory group is integral to LeDeR. This steers our action from learning work and includes people with a learning disability, parents and other family members, and a representative from each of the organisations listed in Appendix 1.

We are also guided by our academic partnership, comprising representatives from King's College London, University of Central Lancashire, Kingston University and St George's, University of London. They produced the 2021 LeDeR Annual Report which included an accessible film version of the 2021 report.

They have produced the LeDeR Annual Report 2022 https://www.kcl.ac.uk/research/leder.

Jack's story

Jack's story of his admission to University Hospitals of Morecambe Bay NHS Foundation Trust demonstrates how person-centred care and reasonable adjustments across health and social care can ensure patients with a learning disability and autistic patients receive fair access to good quality care. It also demonstrates good multi-disciplinary team (MDT) working with Jack at the heart of decision making, and how the role of the learning disability hospital liaison nurse was fundamental to coordinating his complex hospital admission.

> "Jack was delighted to tell me he has no wet beds, no pads and no wetting himself, I am over the moon for him and we are giving lots of praise, reassurance and encouragement and he seems to have forgiven us all for the way he got to hospital."
>
> **Jack's care manager**.

Jack is in his 60s with a moderate learning disability. He is a private person with a fear of healthcare appointments who enjoys the pub and meals out. He moved in to supported living with another tenant after his parents both died.

When Jack experienced kidney problems and incontinence he was brought by his care manager for a urology consultation and became very distressed, refusing to enter the hospital. Although easy read information about his investigations was provided, Jack became upset and refused to engage in any discussions. It was agreed that Jack did not understand the rationale and urgency to see a hospital doctor.

Following a telephone consultation and assessment and an online meeting, the care management team agreed with Jack's family that he wasn't able to understand the proposed medical investigations and probable intervention and therefore lacked capacity to make a decision about his treatment.

A Best Interest Decision was made under the Mental Capacity Act (MCA) concerning Jack's care - with his family, carers, the trust's safeguarding, legal and community learning disability teams (CLDT), the hospital's MDT team, the learning disability liaison nurse/matron and the consultant urologist (the decision maker).

CLDT nurses tried sharing more desensitisation techniques with Jack, however the need for urgent intervention concluded with Jack's family, care managers and the clinical team agreeing to his sedation at home before transfer to hospital for assessment, care and treatment.

A consultant anaesthetist and theatre staff arrived at Jack's home in the morning. An ambulance was parked out of sight until Jack was sedated and settled. Jack's carers supported him during the sedation process and once stable paramedics transferred him to the

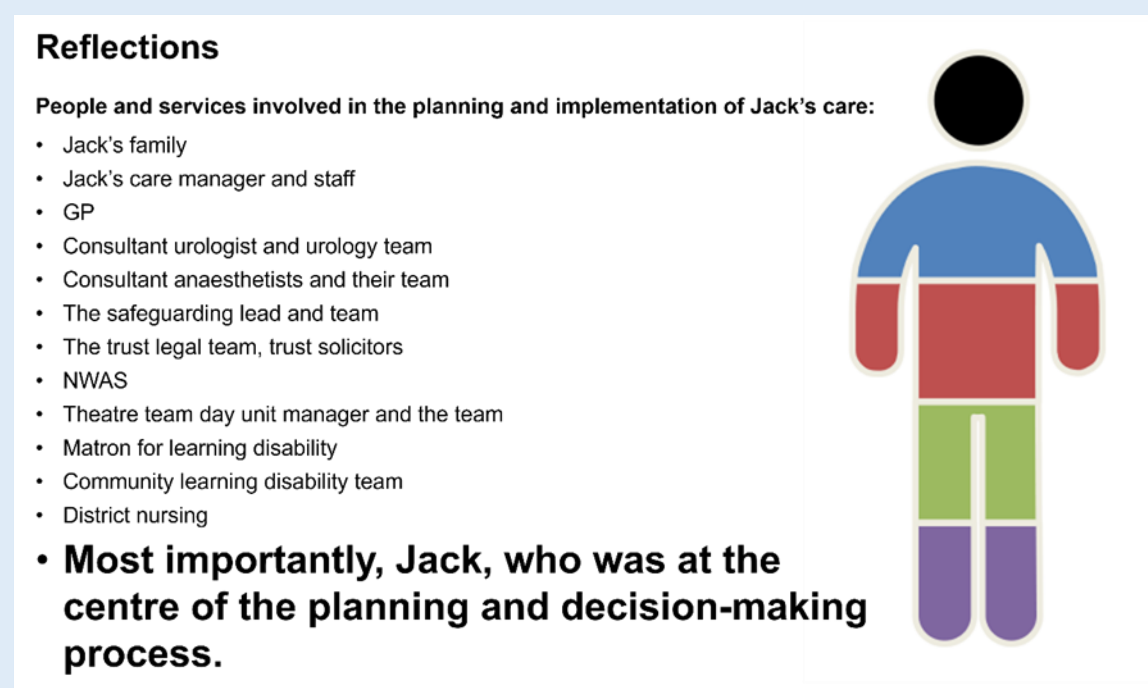
ambulance. On arrival in theatre, a catheter was inserted, and Jack was transferred to the day surgery unit for recovery. He settled on the ward and his niece stayed with him for the duration of his three-night stay.

The same process has been used to facilitate Jack's continued treatment at the hospital, but with reasonable adjustments when needed. For example, when Jack needed renal blood tests but refused to attend, a nurse from his GP practice came to his home to take the blood tests instead. Where possible the urology consultant and specialist nurse also facilitate home visits, while district nurses manage any catheter changes.

The same process has been used to facilitate Jack's continued treatment at the hospital, but with reasonable adjustments when needed. For example, when Jack needed renal blood tests but refused to attend, a nurse from his GP practice came to his home to take the blood tests instead. Where possible the urology consultant and specialist nurse also facilitate home visits, while district nurses manage any catheter changes.

Jack's carers and the learning disability hospital liaison nurse who has known him for over 15 years say that Jack is a 'changed man' since the procedure. Clearly it has enhanced his physical, emotional and psychological wellbeing and improved his quality of life. He is quite proud of his catheter bag, showing it to anyone he can, and his carers think he will be soon be able to empty it himself.

Jack's story is regularly shared by the hospital's learning disability and autism team to cascade the lessons learned from the court, the MDT process, and making reasonable adjustments, with Jack at the heart of all decision making.



This image shows the many people and services involved in the multi-disciplinary approach to Jack's care.

Removing barriers by working together

Collaborative working has also helped address health inequalities while transforming the lives of people with a learning disability and autistic people, in Leicester, Leicestershire and Rutland ICS. Partners from across the system – providers, commissioners and local authorities have worked together to address the gaps in care pathways and turn the service around and into one of the top third for performance in England. Full details of how they improved the service which involved delivering more annual health checks, completing LeDeR reviews more swiftly, and reducing long-term hospital stays, are available online in this collaborative working case study.

Management of medical conditions in 2022/23

Supporting people with COVID-19 vaccination uptake

Large proportions of the UK population have developed at least partial immunity against COVID-19[5] and vaccination is still essential for people with a learning disability who are highly vulnerable to the virus[6].

In Autumn 2022 an NHS campaign urged anyone who was eligible for a COVID-19 booster to come forward, to help increase their protection against serious illness.

In 2022/23 in our work to tackle COVID-19 and increase the uptake of the booster for people with a learning disability and autistic people, we:

- asked the JCVI (which advises UK health departments on immunisation) to update their green book guidance (used by all vaccinators in England) to make sure that the COVID-19 booster is available to everyone on the learning disability register aged 5 years and over
- promoted the reasonable adjustments available to support COVID-19 and flu vaccinations by releasing a short film about Rachel and her mum Carol
- worked with the COVID-19 vaccination programme to improve uptake guidance for people with a learning disability which includes examples of good practice, and references LeDeR outcomes for making every contact count. The guidance is available on the FutureNHS platform (For NHS staff)
- sent an easy read letter in Autumn 2022 to invite everyone aged over 5 years and on the learning disability register for a COVID-19 booster
- raised awareness at several stakeholder and engagement events on reasonable adjustments and what they may look like, provided links to information, case studies, accessible information, answered questions, and supported understanding of the JCVI guidance to promote informed and best interest decision making
- worked with the communications team on a national campaign to get the message out through special schools and to parents about the booster being offered to both children over five years and their carers.

We also reminded health and social care staff who were sent reminders for their own booster of the importance of encouraging uptake in those they care for.

[5] Independent report - Joint Committee on Vaccination and Immunisation (JCVI) updated statement on the COVID-19 vaccination programme for autumn 2022

[6] The *BMJ* 2021;374:n1701 - Covid 19: People with learning disabilities are highly vulnerable

When compared to uptake among the general population, the uptake of vaccination among people with a learning disability was in line with the general population and proportionately higher in the 30-49 age group[7].

NHS England regional teams

Our regional teams have continued working with the national NHS COVID-19 vaccination programme to ensure people with a learning disability and autistic people have appropriate and timely access to vaccinations, and that where necessary primary care staff make any reasonable adjustments to help with this.

Vaccine booster clinic in South London

Students who attend the Share Community Centre in Battersea, South London received their combined COVID-19 autumn booster and their flu vaccination over the course of an afternoon in December 2022, when staff from the training centre worked with local GPs to provide a vaccination clinic. The centre, which provides learning and wellbeing resources to help adults with a learning disability and autism to live life to the full, provided a safe and familiar environment where its members could take as long as they needed to receive their vaccinations. In this short film about the vaccine booster clinic, Steve Russell, National Director for Vaccination and Screening at NHS England talked to the GPs and nurses who ran the clinic to find out what reasonable adjustments were offered.

This image shows two of the students featured in the short film who attended the Share Community Centre combined vaccination session together. Both students thanked the nurses who they said were “very friendly” and had “done a great job”.

[7] Primary course and booster dose vaccinations statistics for the Learning Disability population taken from NHS Foundry system using NIMS data - as reported 25th February 2023. (NIMS is the System of Record for the NHS COVID-19 vaccination programme in England.)

Continuing COVID-19 safeguards

The self-advocacy group People First Merseyside, which is run by and for people with a learning disability, is one of many organisations that have kept some measures in place to prevent the spread of COVID-19, even after social distancing restrictions were lifted. To reduce the risk of infection, the organisation encourages people to:

- have their temperature taken on arrival at the centre
- stay away from the centre if they are feeling unwell, particularly with any cold or flu symptoms
- take up any relevant COVID-19 booster and flu vaccinations.

Most of the group's 40 core members have had their COVID-19 booster and People First Merseyside continues to encourage others who they engage with externally to have any relevant vaccinations. The group also continues to work with the public health team in Sefton Council to ensure any messaging about COVID-19 is accessible for people with a learning disability or autism.

A thematic analysis of COVID deaths in the Midlands

Leicestershire Partnership NHS Trust, like trusts across England, has been driving improvements based on learnings from the pandemic.

LeDeR clinical leads at Leicestershire Partnership NHS Trust analysed 28 LeDeR reviews into the deaths of people with a learning disability between 2020 and March 2022 where COVID was recorded on the person's death certificate as their cause of death.

Many examples showed good quality care at home and appropriately offered reasonable adjustments with multiple agencies and professionals working together.

The analysis also found four key areas for improvement in the treatment of people with a learning disability in both acute settings and in the community. These included: communication, applying the Mental Capacity Act and best interest decisions, record keeping, and diagnostic overshadowing.

A series of specific actions were developed and shared to partner agencies and community services to realise changes and learning for the future. These included:

- using hospital passports
- engaging meaningfully with parents and carers
- centralising access to health and social care systems
- reviewing training to ensure that learning is embedded.

A new learning disability assessment has also been implemented at University Hospitals of Leicester NHS Trust (UHL) to highlight any reasonable adjustments a person with a learning disability may require. Primary Care Liaison Nurses can also use the data from the thematic review to offer personalised training at every GP practice.

Respiratory conditions

The LeDeR Annual Report 2021 found that, when looking at individual long-term health conditions of people who died in 2021 and had an initial LeDeR review, 17% of those who had a long-term respiratory condition had an avoidable death. People with dysphagia (swallowing difficulties) are also at an increased risk of respiratory conditions including aspiration pneumonia. NHS.uk defines aspiration pneumonia as 'pneumonia caused by breathing in vomit, a foreign object, such as a peanut, or a harmful substance, such as smoke or a chemical'.

There was a notable reduction in numbers and proportions of deaths due to pneumonia in the LeDeR Report 2021 compared to previous years which may be due in part to social distancing measures and some pneumonia deaths being classified as COVID-19.

Preventing, diagnosing and managing poor respiratory health is a priority in the care of people with a learning disability.

New national guidance on pneumonia

Two key respiratory care projects commissioned by the national LeDeR team have now been delivered:

1. The British Thoracic Society (BTS) which champions 'Better lung health for all' produced two statements on pneumonia. These statements are guidelines on the management of the infection and summarise the best evidence to date. The two statements are:

i. Guidance on aspiration pneumonia (AP)

ii. Guidance on community acquired pneumonia (CAP) in people with a learning disability.

Both statements were published in March 2023 after extensive consultation and arose because pneumonia and aspiration pneumonia are disproportionately represented in people with a learning disability and are a major cause of death'[9]. This guidance was co-produced with people with lived experience and will help health professionals improve the care of people with a learning disability who have or are at risk of pneumonia

[9] University of Bristol. The learning disabilities mortality review (LeDeR) programme, annual report, 2019.

2. The NHS RightCare programme, which makes recommendations to improve healthcare, has developed a new RightCare pathway scenario for aspiration pneumonia care. The guide identifies best practice in preventing and treating aspiration pneumonia and is for use by providers and commissioners in planning and delivering evidence-based care.

The LeDeR team also co-hosted respiratory webinars for healthcare professionals to present the new BTS statements in March 2023 and the RightCare pathway in July 2023. Neary 350 people attended both the RightCare and BTS webinars.

Staying Well this Winter

We were asked to think about what we could do to support people with a learning disability and autistic people to stay well over winter. Respiratory illnesses are more common in winter and are a leading cause of death for people with a learning disability, and the rising cost of fuel is a concern for many people with a learning disability and their family/carers.

We worked with experts by experience, stakeholders to review any gaps in wellbeing information – and then supported the production of the 'Stay well this winter' resource. This easy read leaflet includes guidance on things people can do to stay well in winter including having relevant vaccinations, keeping warm, keeping active, where to go for the right medical care and looking out for others.

The front page of the Stay Well this Winter flyer.

Dysphagia

Dysphagia (swallowing difficulties) was the fifth most common reported long-term health condition[10] for people with a learning disability who died in 2021 and received an initial LeDeR review. Dysphagia is more common among people with a learning disability than in the general population. Improving dysphagia risk management, information and treatment has been a focus in many Integrated Care Systems. This includes training around posture and associated respiratory risks and symptoms as people with dysphagia are more at risk of developing pneumonia and increased mortality.

Dysphagia awareness in the South West

A number of initiatives in the South West region are improving the management of dysphagia for people with a learning disability. These include:

Dysphagia training in Devon

A group of specialist speech and language therapists (SALTs) working in learning disability services across Devon Partnership NHS Trust created a 90 minute online dysphagia training course with funding from the Devon LeDeR programme. This was based on local learning that dysphagia was the second most common long-term health condition, after pneumonia and aspiration pneumonia, reported for people with a learning disability who have died in the county.

The course was designed for anyone supporting individuals with a learning disability with their eating and drinking and raises awareness of dysphagia, to improve health outcomes and prevent premature death. It includes information on what conditions might affect swallowing, spotting the signs of swallowing difficulties, following eating and drinking guidelines on how food and drink might be described for example, ‘pre-mashed’ or ‘thin puree.’ The course gave guidance on how a SALT could help and when to refer to them. The SALT team also created an awareness poster that was showcased on screens in GP waiting rooms across Devon.

Swallowing awareness

In Bristol, North Somerset and South Gloucestershire (BNSSG) ICB, the learning disability team created a new swallowing awareness flyer to raise awareness of the common signs of dysphagia and the risk of choking due to dysphagia or aspiration pneumonia. It included a call to action for carers to contact the SALT

[10] LeDeR Annual Report 2021 (Page 20) https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf

team or the person's GP if they had any concerns. The flyer was distributed to over 400 care homes. The ICB established a new dysphagia group in April 2023 with people with a learning disability which will teach people who have dysphagia about their condition. The dysphagia group will explore how they can make food appetising and safe, working with professional chefs. Finally, the team are also training care staff in how to support people with dysphagia.

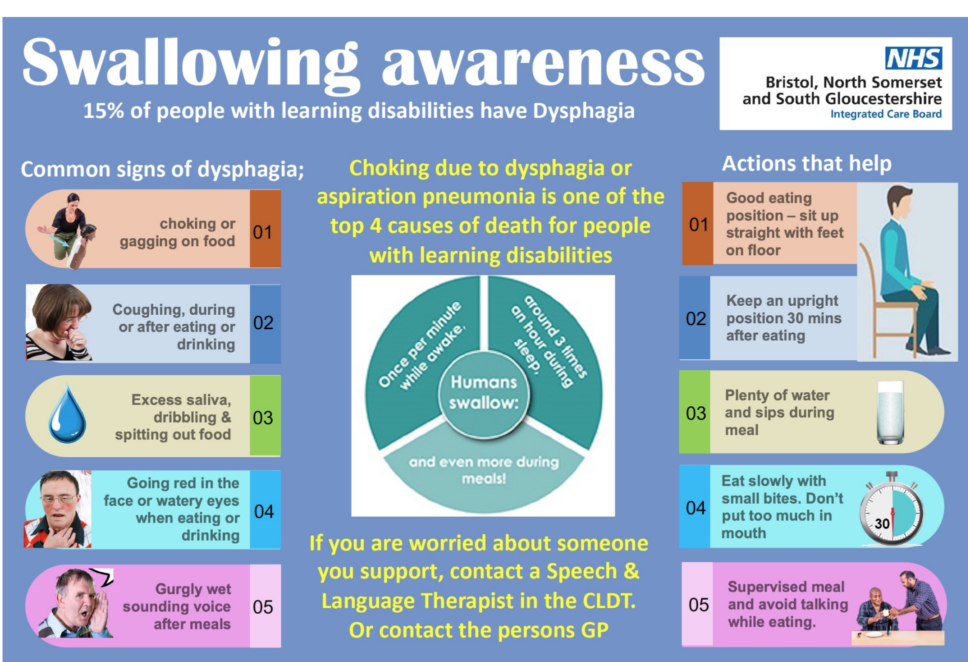
Improving Dysphagia management in the South West

The South West NHS England Learning Disability and Autism Programme Team hosted an online dysphagia management event in December 2022.

The session provided an opportunity for health and social care providers, people with lived experience, commissioners, and others to share learning and to consider the barriers and opportunities to the effective management of dysphagia.

Attendees at the event decided on tangible actions that could improve dysphagia management across the South West and a multi-professional working group was formed following the event. The group is now developing a knowledge and skills framework to support paid carers in the effective management of dysphagia, based on Royal College of Speech and Language Therapy guidance. The framework will be for paid carers who prepare food and support people who have a learning disability with eating and drinking. It will be tested in two care providers in summer 2023 and the aim is it will be more widely available by the end of 2023.

The South West regional team also created a [FutureNHS: dysphagia resources]() webpage to support the management of the condition.



This image shows a dysphagia awareness flyer which BNSSG ICB distributed to over 400 care homes.

Seasonal flu vaccination

'Influenza and pneumonia' was one of the most frequently cited causes of death (for all ages) reported to LeDeR between 2018 and 2021. LeDeR reviews have shown that some people with a learning disability miss out on Annual Health Checks (AHCs) and flu vaccination. Flu can be serious, even when someone is healthy, however the flu vaccine can reduce the severity of the illness. People with a learning disability and their carers (a family member or support worker) are eligible for a seasonal free flu vaccine every year.

What we did during Winter 2022/23:

We supported the campaign to encourage people with a learning disability and autistic people and any relevant carers, to take up flu vaccination.

This included:

- making information about the importance of flu protection more accessible by updating and producing new accessible materials, (with the UKHSA), including a new Easy Read leaflet for people with a learning disability to 'Protect yourself from the flu'
- ensuring our messages were getting out by liaising with communications teams from the Department of Health and Social Care (DHSC), NHS England and Public Health England (PHE)
- working on public health messages and expanding eligibility for access to the flu vaccine among people with a learning disability with colleagues in the NHS Immunisation Management Service (NIMS) and UKHSA
- presenting at a webinar for stakeholders and GPs run by our communications team on flu vaccinations and reasonable adjustments for people with a learning disability
- targeting areas of concern on the take up of the vaccine (mostly children and young people) by reviewing the data and focusing communications work
- working with NHS England regional teams on their flu campaigns
- targeting different people who were eligible for a flu vaccination – parents/carers and individuals and one for professionals - in a national communications campaign on social media from August 2022
- supported the new programme to improve vaccination uptake guidance for people with a learning disability which includes examples of good practice, and references LeDeR outcomes for making every contact count. This guidance incorporated learning from LeDeR outcomes and from the innovative work in vaccinations during the COVID-19 pandemic. It is available on the FutureNHS platform (For NHS staff)
- working to improve people's health and wellbeing by having COVID-19 and flu vaccinations administered together and meeting people's specific needs, including any needle phobias by working at a local level to support the MECC approach (making every contact count)

- supporting regions with local specialist flu/COVID vaccination clinics, using vaccinators from specialist services who had been trained to deliver COVID and had already built good networks to support flu vaccination programmes
- ensured case studies were including people with a learning disability and were added to the FutureNHS Flu pages.

Finally we supported the production of a video – a guide for parents and carers of people with a learning disability on flu vaccinations. Aaron Senior, a lived experience autism advisor with NHS England, features in the film receiving his flu vaccination.

Identifying and managing deterioration in health

Some people with a learning disability and some autistic people cannot easily communicate that they feel unwell and their health may deteriorate very quickly.

The LeDeR Annual Report 2021[12] found that, in social care settings, a lack of recognition of deterioration in physical health and, in particular, a lack of recognition of when and how to seek medical support could lead to 'delayed escalation' of care.

The earlier we can spot a health concern and start treatment the better.

We have developed several initiatives to help identify and manage deterioration in health and to prevent avoidable deaths – described below.

RESTORE2 mini

We worked with the charity Skills for Care, which supports the adult care sector, to make the RESTORE2™mini training more accessible for carers across England. This tool has been adapted for use in care homes to help carers detect the 'soft signs' of deterioration to facilitate earlier treatment. The training tool and training slides are now available on the Skills for Care website.

Decision support tool for physical health – training

We funded Cheshire and Wirral Partnership NHS Foundation Trust to deliver more face to face training on the 'decision support tool for physical health' or ('DST-PH')which will help health system staff proactively identify people with a learning disability who are at risk of premature mortality or preventable death.

[12] LeDeR Annual Report 2021: King's College London et al. Page 52

Training was delivered to organisations including Surrey and Borders Partnership NHS Foundation Trust, London ADASS network (all the learning disability services in the London area), the Learning Disability Senate, members of the Royal College of GPs and the national learning disability Nurse Consultant Forum. Training in DST-PH is also included in the Physician programme run by Edge Hill University in partnership with the RCP. The toolkit was presented at the Royal College of Psychiatrists International Congress in Liverpool in July 2023.

The Trust also developed a free online resource package of guides, videos, and PDFs to explain how to effectively complete and use the tool in clinical practice. The training in the tool will be offered to ICBs across the North West and further pilots are underway as part of the North West's physical health workstream.

Identifying individuals at risk - a primary care pilot

Sussex Partnership NHS Foundation Trust in partnership with Sussex ICB has also successfully piloted the implementation of the Dynamic Support Tool- Physical Health 'DST-PH' at three GP practices. The Sussex partnership now hopes to extend the pilot to more practices in 2023, to explore the feasibility of delivering the tool with AHCs, and to develop a series of user-friendly resources.

There is evidence that the DST-PH has effectively reduced emergency admissions and is helping to keep people with a learning disability out of acute hospitals.

Preventing and identifying frailty in Hertfordshire

A new tool based on learning from LeDeR and NICE recommendations has been piloted throughout 2022/23 in the East of England to identify sooner the risks of frailty among people aged 18 and over with a learning disability. Frailty is defined by the NHS as 'where someone is less able to cope and recover from accidents, physical illness or other stressful events.' The NHS also states that frailty should be treated as a long-term condition throughout adult life and its prevention and early identification is essential to supporting people appropriately.

Some people with a learning disability are at more risk of frailty, for example, if they have diabetes, heart valve disease, or are on multiple medications. This is not always obvious and the earliest opportunity to spot the risks of frailty might be during unplanned episodes of care.

Frail+LD has been created by both Hertfordshire's County Council (in consultation with Hertfordshire and West Essex ICS and Hertfordshire Partnership Foundation Trust colleagues) and is being piloted with support from the University of Hertfordshire / Eastern AHSN The tool uses indicators[13] to highlight where staff can mitigate the risk of frailty or refer someone with a learning disability to the frailty pathway. It might look at medication, any missed health screenings, health changes, support network, or why someone is having falls.

[13] The tool has been developed because it is advised that the (Rockwood) Clinical Frailty Scale should not be used in isolation with people with a learning disability.

The Frail+LD tool can be used across disciplines and by GPs, nurses, social workers, and occupational therapists to pinpoint areas of a person's risk of frailty and proactively assess and manage their health and support needs. It is being used for everyone with a learning disability who is known to Herts County Council and in people's homes, care homes or wherever someone is working with a person with a learning disability. The frailty indicators (see image) have also been added to the preparation tool checklist for carers to help them identify changes to health before someone has their annual health check.

The tool was independently evaluated in March 2023 and focus groups were conducted with people with a learning disability who have been assessed by the tool. Of those assessed 51% have been identified as at medium or high risk of frailty developing, and 11% have been referred to and accessed a frailty clinic. Practitioners were also asked to score the frailty risk prior to completing the tool based on their professional judgement – in 22% of cases the tool identified a risk of frailty where the practitioner had not. The tool is being rolled out across Hertfordshire and West Essex ICS.

FRAIL+LD - FRAILTY INDICATORS FOR PEOPLE WITH LEARNING DISABILITIES

eQUALITY

Hertfordshire

These risks should be considered where indicated for any patients with learning disabilities aged 18 and above to enable more proactive management of changes to health. People with Learning disabilities are at increased risk of vulnerabilities relating to unquantified changes to health due to growing older.

Name: DOB: NHS no:

Indicators	Level of risk					
	Mild	Tick √	Moderate	Tick √	Severe	Tick √
Disease	• 1 physical health condition that is managed well		• 2 health conditions requiring regular reviews - e.g. swallowing problems, nutritional deficit, prone to infections		• More than 2 known health conditions • Any health condition not well managed	
Management	• Health issues managed with medication and adequate support e.g. specialists		• Health condition requiring reviews beyond annual health check • Stable health not sustained		• Significant health needs combined with a history of behavioural challenges that are complex to manage. • Unmet needs	
Insight	• Has good insight into condition • Able to take necessary actions with or without support		• Has limited insight into own health issues • Able to take health advice or engage with necessary actions with support		• Has no insight into own health needs • Non-compliant with care • Self-neglect e.g. non-adherence to appointment, poor hygiene, not reporting health decline. • Lack of engagement leading to lack of support	
Engagement	• Engaging well • Attends regular health services e.g. GP, dentist, annual health checks, takes prescribed medication		• Not engaging with health recommendations e.g. poor dietary and lifestyle choices • Fluctuates in accessing health care services • Lack of proactive staff support		• Lack of engagement – not attending health appointment, declining health support, DNAs • Non-compliant with care • Self-neglect poor hygiene, not reporting health decline. • Declines all support – health needs unmanaged	
Support	• Living independently or with minimal support and coping well		• Requiring support with some ADL • Significant mobility issues • Daily support needed to manage health needs • Unmanaged needs putting placement at risk		• Requiring 24hour support • Living in an inappropriate environment and has a significant health issue • Requiring support with all ADL	
Admission	• No unplanned admissions in the last year		• 1 - 2 hospital admissions in the last year		• More than 2 hospital admissions in the last year	
Decline	• No recent major health decline		• Health has declined in the last year		• Health has declined in the last month	
Behaviour patterns & Risk of Falls	• Patterns of behaviour do not pose any additional risks to health • No falls		• Behaviour patterns contributing directly to health risk • 1 – 2 Falls in a year		• Known safeguarding history (health related) • High incidence of falls - more than 2 in a year	
Recommendations:						

© 2021 Hertfordshire County Council

The image shows the frailty indicators for people with a learning disability.

Constipation

People with a learning disability are at greater risk[14] of constipation. Some people with a learning disability may also find it difficult to communicate their problem Constipation was one of the 10 most frequently reported long-term health conditions among people with a learning disability who died in 2020 (55%). Over a third of those whose deaths were reviewed in the LeDeR 2020 annual report were usually prescribed laxatives (38%)[15]. Kings College London (KCL) have led a 'deep dive' on constipation related deaths in the LeDeR data. Their key findings include actions for clinicians and carers. Their full report along with an easy read version will be available soon. This study showed that 13% of people identified as having constipation died of causes of death such as bowel perforation and obstruction which are associated with constipation. Appropriate use of laxatives can be helpful but should not replace a healthy diet, adequate hydration, and appropriate exercise.

Our work to address constipation in 2022/23

We commissioned a new national constipation campaign toolkit which launched in July 2023 to raise awareness of the risks that constipation can pose to people with a learning disability. This focused on people with a learning disability, their paid and unpaid carers, and general practice and pharmacy staff, to help them prevent, recognise, and treat constipation in people with a learning disability.

We have produced accessible materials and content for GP practices and websites used by social care staff. Materials were distributed across stakeholder networks, to professional bodies and through NHS England channels and relevant social media platforms.

The South London and Maudsley NHS Foundation Trust have developed an app to help clinicians check if the medication they are prescribing could contribute to constipation. The Medichec app will help them decide whether to carry out a medication review or to prescribe a different medicine. The updated app is due for release in Autumn 2023.

KCL have led a 'deep dive' on constipation related deaths in LeDeR data. Their key findings which are available here, include actions for clinicians and carers. Their full report along with an easy read version will be available soon.

---

[14] LeDeR bulletin, January 2019: Constipation: Dying for a poo.

[15] LeDeR Annual Report 2021 – KCL, et al. Page 47.

Cancer

The LeDeR annual report 2021[16] found areas of concern in primary and community care, around a lack of preventative healthcare (screening programmes and vaccinations) and difficulties accessing appointments. In some cases, this was founded on a lack of reasonable adjustments, including not providing information in suitable formats, or discharging a person from a community or out-patient service following a single non-attendance.

Screening prevents disease and can save lives. The uptake in screening for breast cancer and cervical cancer among people with a learning disability and autistic people is lower compared to the general population and uptake in bowel cancer screening can be difficult for some people with a learning disability without additional support[17].

Our work in cervical cancer screening

During Cervical Cancer Screening Week in January 2023 NHS England shared Jodie's film - Accessing cervical screening with the right support for people with a learning disability. In the film Jodie, who works with the NHS England Learning Disability and Autism team and has a mild learning disability, shared her experience of accessing her first cervical screening at the age of 40 by talking to her GP practice and her learning disability nurse to make sure the right reasonable adjustments were made for her. The NHS Cervical Screening programme is available for all women and people with a cervix aged 25-64 and easy read information and a video about cervical screening for people with a learning disability is available at Jo's Trust.

Image is a screengrab from Jodie's video in which she describes her experience of cervical screening

[16] LeDeR Annual Report 2021 – KCL, et al. Page 47.

[17] Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD), 2013 https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf

We have worked with national screening programmes and health inequalities leads to share good practice across both programmes to reduce health inequalities in cancer diagnoses and treatment. In addition:

- NHSE has introduced a phased reduction for the age of bowel cancer screening since April 2021 and will eventually include all people aged 50 to 59. Screening invitations were previously for over 60s.
- We supported a new film from Sutton Mencap encouraging people to have their bowel screening, explaining how to use the bowel screening kit and describing how to spot some of the symptoms of bowel cancer.
- We worked with the national bowel screening campaign ensuring all resources were accessible and included people with a learning disability. A step-by-step film on how to use the bowel cancer screening FIT kit was also shared widely.
- We promoted the new resources which were created by the Primary Care Network (PCN) Cancer Facilitator for the West Yorkshire and Harrogate Cancer Alliance across all screening leads, learning disability and autism leads and cancer networks across England to help increase screening uptake. The facilitator worked with Bradford Talking Media to create three accessible videos for people with a learning disability and their carers. The videos – on bowel, breast, and cervical screening – describe the process from screening invitation through to test results.
- We are supporting research from The University of Glasgow in to the experience of screening for breast, bowel, and cervical cancers among people with a learning disability and how access can be improved.

Have your bowel cancer screening

If you are aged over 55, you will soon be sent a **free** NHS bowel cancer screening kit in a box.

The kit comes through the post. The kit tests for early signs of bowel cancer.

The test is easy to do and does not hurt. You can ask someone you trust like a family member or carer to help.

When you have done the test, put the box into a post box.

Your results will be checked. A nurse will contact you if there is a problem. Finding cancer early makes it easier to treat.

If you have any questions please call 0800 707 6060
Find out more at healthylondon.org/BCS

Image is an NHS poster about bowel cancer screening

The NHS Cancer Programme's work

The NHS cancer programme has worked closely with LeDeR to tackle health inequalities in screening, diagnoses, and treatment. Their work in 2022 included:

Reviewing experiences of cancer care

In 2021/22, the NHS Cancer Programme looked at evidence and data about the experience of cancer amongst different patient groups, including people with: mental health difficulties, dementia, learning disability and autistic people.

The national cancer patient experience survey

The National Cancer Patient Experience Survey (CPES) also gave insights into variations in experience of cancer care. As part of the CPES the team looked in detail at the results of the survey from different groups including from 191 people with a learning disability surveyed in 2021. These 'deep dives' revealed the following themes of areas for improvement in service:

- in reasonable adjustments - such as having a quiet room to wait in
- in telling people bad news – i.e. staff need to think about the words they use when they tell people they have cancer and talk to people with a learning disability about cancer.

The results of the most recent national report (2022) and of the latest published deep dives (2021) are available in easy read.

A mental health and cancer thinking group

In 2022, the NHS Cancer Programme invited a group of experts and people with lived experi-ence to consider how to improve cancer care for people with a pre-existing mental health con-dition. The group co-produced an action plan and identified areas for improving experience of care mainly focused on people with a mental health condition. The group also created new resources and held a conference on improving mental health for people affected by cancer in 2022 to raise awareness of health inequalities in experience of cancer care.

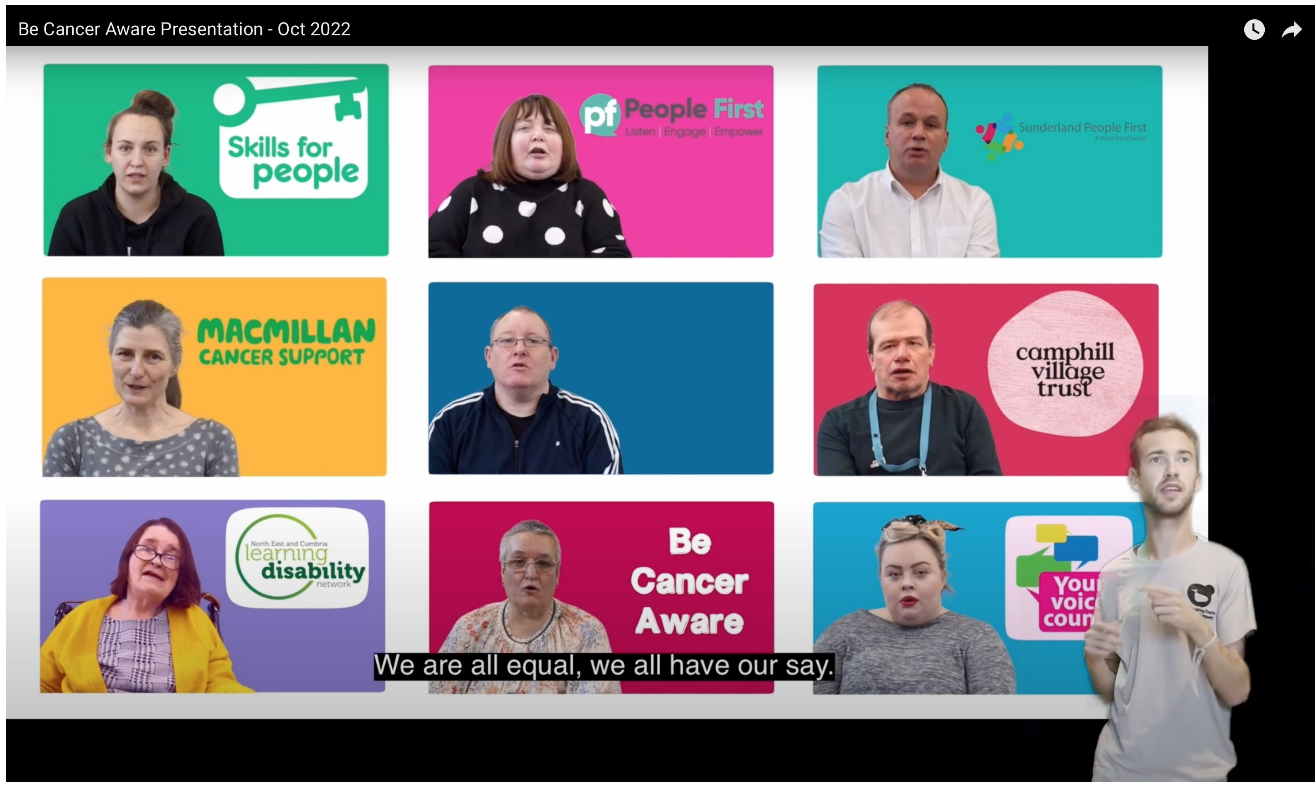
The conference was attended by Cancer Alliances*, people with lived experience, carers and charities and shared patient stories and workshops. One workshop focused on 'Improving experience of cancer care for people with a learning disability and autistic people and their carers' while other themes focused on the importance of cancer care teams working closely with learning disability hospital liaison nurses and ensuring reasonable adjustments for individuals where needed.

*Cancer Alliances bring together clinical and managerial leaders from different hospital trusts and other health and social care organisations, to transform the diagnosis, treatment and care for cancer patients in their local area. These partnerships enable care to be more effectively planned across cancer pathways.

The Cancer Experience of Care Improvement Collaborative (CIC) for 2023/24, (launching in September 2023) is focusing on improving experiences of cancer care for people with pre-existing conditions including learning disability and autism, in part because of the findings from LeDeR reviews.

Be Cancer Aware – a co-produced course in the North East

The North East and Cumbria Learning Disability Network and the Northern Cancer Alliance have continued their work with self-advocacy groups including Skills for People and Sunderland People First to co-produce their 'Be Cancer Aware' sessions, which they are now delivering to the learning disability community across the region. Their presentation in October 2022 (available here on YouTube) explains their work.



A Screengrab which shows the various self-advocacy groups which have co-produced the 'Be Cancer Aware' course.

Transforming Cancer Services for London

The pan-London Transforming Cancer Services team* (TCS) and Primary and Community Care Education Group led a workshop in May 2022 on improving cancer outcomes for people with a learning disability in. The attendees included Cancer Alliances, ICSs, GPs, oncologists, nurses, third sector organisations and Allied Health Professionals. They heard details from LeDeR reports, listened to the story of Annie, a woman with a learning disability and met experts by experience to better understand experiences of a cancer pathway.

Several recommendations from that session are now being implemented including: reviewing the two-week cancer pathway across the community and in primary care to specifically address health inequalities.

The team has considered some of the barriers people with a learning disability may experience while on a ‘two week wait’ referral. Patients may need:

- easy read materials explaining the appointment before they attend
- additional support to ensure they attend an appointment
- a key worker or other support at the appointment
- reasonable adjustments.

TCS has also standardised the cancer referral form used across London ensuring that it is fit for purpose where patients may face additional health inequalities. This standardised form will also help to address consistency in referrals, as up to 25% of GPs in London are locums. The form which launched in January 2023 also includes links to the clinical guidance and patient resources. The team are making easy read formats and have so far produced an easy read version of the Urgent Suspected Cancer Patient Information leaflet.

The Transforming Cancer Services team are also ensuring that GPs can easily find a learning disability link nurse for example when they refer a patient to the cancer pathway who has a learning disability. They are also supporting the pan-London cancer screening board to increase the uptake of cancer screening among people with a learning disability.

*The Transforming Cancer Services Team (TCST) is a pan-London team of 15 staff and is part of Transformation Partners in Health and Care. TCST is a collaboration between London ICSs and NHSE London. It is responsible for implementing the national cancer strategy, diagnosing cancer earlier and faster.

Tackling inequalities - a South West screening liaison service

Following the success of the Cornwall Screening Liaison Service, NHS England South West Vaccination and Screening Team secured funding for a practitioner post across the other six ICBs in the South West. This practitioner role will deliver a local service to increase the uptake and engagement in screening among adults with a learning disability.

The Cornwall screening liaison service ensures appropriate access to screening and reasonable adjustments are in place when required. Its three screening liaison nurses are part of Cornwall Partnership NHS Foundation Trust's adult community services.

They support people with a learning disability across the five screening services - breast cancer, bowel cancer, diabetic eye screening, cervical cancer and abdominal aortic aneurysm (AAA) screening - and help the person to make an informed choice on attending any appointment. They also provide support for their family/carer to help people access screening.

Their work includes but is not limited to:

- Supporting the person to attend an appointment
- Discussing fears or concerns with the person, their families and their carers
- Supporting access needs – for example the area's mobile breast cancer screening van has no wheelchair access, so the team will arrange appointments at hospital when required
- Providing easy read materials and some bespoke materials. For example, the team created a bespoke easy read for a gentleman who needed a colonoscopy
- Contacting patients on a GP's learning disability register who have not completed their bowel screening to offer support, advice and a home visit – including demonstrating the bowel screening Fit 120 kit
- Ordering bowel screening kits for people who choose to participate
- Supporting desensitisation sessions

For cervical screening, as an example, the team:

- ask GP practices to check their learning disability register for women and people with a cervix who did not attend, cancelled or declined to attend an appointment and follow up to find out why
- offer training and advice to GPs, nurses and care/supported living homes
- can act as a chaperone.

The nurses also work with primary care, health promotion teams, charities, learning disability services, acute liaison nurses and adult social care and have links with the radiographers who provide specific clinics for people with a learning The team also ask GPs to use annual health checks to prompt people on applicable screening.

In 2022, the uptake for bowel screening for people with a learning disability was considerably higher in Cornwall and the Isles of Scilly ICB (at 60.29%) compared to the wider Southern Hub (49.95%). Breast screening uptake was almost the same as for women in the general population.

Tackling barriers to cervical screening in Hertfordshire

A fleet of new resources, a new cervical screening pathway and a Cervical Screening Decision Process Tool were developed in 2022 by Herts Valley CCG - to reduce barriers to cervical screening among women and people with a cervix who have a learning disability. The resources were funded as part of the project with NHS East of England Cancer Alliance and inform GP practice staff about the importance of cervical screening and supporting women and people with a cervix to access it.

The cervical screening decision process tool and pathway can be used by any practice nurse/ screener and aims to ensure every possible step has been taken to check the person's capacity to make an informed decision and understand the risks of not being screened, and then ensure every step possible is taken to overcome the barriers, make reasonable adjustments, and where applicable, make best interest decisions weighing up the risks and benefits.

The resources and the Check it Out! film about cancer screening made by the Purple All Stars group whose members have a learning disability are being shared with practices across Hertfordshire and the wider East of England Cancer Alliance.

Raising the risks of breast cancer in Worcestershire

In November 2022 the community learning disabilities team at Herefordshire and Worcestershire Health and Care NHS Trust ran an event to encourage women with a learning disability to access routine - and vital - breast cancer screening. The 26 women who attended the 'My Breasts and Me' event at the Worcestershire Breast Unit had a meet and greet with the radiographer, they explored the mammogram machine, and nurses from the unit demonstrated to the women how to check their breasts and what changes to look out for – and how to tell a GP or someone they trust if they noticed changes. Easy read materials supported the event and everyone who attended was made to feel very welcome. The team now intend to make this an annual event.

'Know Your Body' resources

Ansar Projects, part of the Thera Group, which supports people with a learning disability, launched a series of new easy-read resources in October 2022 to support people with a learning disability to know their own body. Produced in partnership with two cancer charities – Coppafeel! and Orchid – and influenced by questions from people with lived experience, the resources raise awareness around breast cancer and testicular cancer. They also include accessible health information, body diaries, self-checking cards and a 'What happens next?' series explaining what to expect at check-ups and tests. Although produced independently from the NHS, LeDeR statistics around avoidable deaths really highlighted to the team the importance of these resources being developed.

Epilepsy

Epilepsy is a condition that affects electrical activity in the brain, and this causes seizures. Nearly one in three people with a mild to moderate learning disability has epilepsy – and those with a severe learning disability or those who are autistic are even more likely to.

Rates of epilepsy are significantly higher in people with a learning disability (20%) and autistic people (ranging from 20-40%) than the general population (1%). The 2021 LeDeR Annual Report found that Epilepsy was the most common long-term health condition associated with an earlier age at death'[18].

People with a learning disability and autistic people can also experience poorer quality of life and see variation in the quality of epilepsy care received. Successive LeDeR reports and national reviews, such as the Clive Treacy Independent Review and the Norfolk Safeguarding Adults Board Review into the deaths of Joanna, 'Jon' and Ben make an urgent case for action to tackle these inequalities. We produced a video about epilepsy care nurses.

My life with epilepsy – new resources

We funded SUDEP* Action to improve and develop the information and resources available to support people with a learning disability and autistic people through their 'My Life with Epilepsy' initiative. They worked with Speakup self-advocacy group, Cornwall Partnership NHS Foundation Trust, University of Plymouth's Peninsula School of Medicine, and University of Sheffield's School of Education.

* SUDEP means the sudden, unexpected death of someone with epilepsy, who was otherwise healthy.

The new resources, published in April 2023, will help people to better understand their epilepsy risks. SUDEP Action engaged many stakeholders throughout the project; more than 30 experts by experience were directly involved in co-designing the resources (autistic people and people with a learning disability), seven bereaved families supported the project by sharing the stories of their loved one who died, and more than 530 people - care providers, health professionals and others - have engaged with SUDEP Action on the project or provided feedback on the resources.

The fleet of new and updated resources includes:

- A background report – giving an overview of the research into epilepsy risks in people with a learning disability and autistic people
- An easy read leaflet on epilepsy risks for people with a learning disability
- A plain English leaflet on epilepsy risks for autistic people

A leaflet on epilepsy risks for carers/family members/support workers of people with a learning disability and autistic people living with epilepsy.

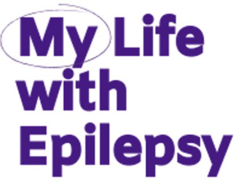
[18] LeDeR: learning from lives and deaths – people with a learning disability and autistic people 2021. King's College London et al. (Page 56).

- A video on epilepsy risks and how to live more safely with epilepsy for people with a learning disability and autistic people
- A video on epilepsy risks for carers/family members/support workers to help them support people with a learning disability and autistic people, and epilepsy.

All the resources are available on the SUDEP Action website.

As part of this project, leading epilepsy and learning disability experts reviewed SUDEP Action's EpSMon app, (which can be downloaded on that site for free), to see how it could be redesigned to better support people with a learning disability or autism to monitor the condition. SUDEP Action have now created a usability report to inform updates to the next version of EpSMon.

- Co-designed resources led by experts by experience
- ICS network support and involvement
- Bereaved families consulted
- Background research report published



Resources coming soon:

- Easy read Epilepsy/SUDEP risk leaflet
- Epilepsy/SUDEP Risk leaflet for carers (family/paid)
- Videos on risk for people with learning disability and epilepsy, and for family/paid carers.
- Feedback on EpSMon– how to make it as accessible as possible to people with a learning disability & epilepsy and their family/carers.

Scan the QR code to find out more

An image explaining the My Life with Epilepsy resources.

Improving Epilepsy Care in the Midlands

The NHS England Midlands Learning Disability and Autism Programme began a new programme of work in late 2022 to reduce avoidable death by further understanding and improving the provision of epilepsy services for people with a learning disability and autistic people. This work has been influenced by learning from the life and death of Clive Treacey.

This work included:

Regional epilepsy conference

In October 2022 over 300 people attended a regional epilepsy webinar delivered by the Midlands team. The attendees included national epilepsy experts and regional leads who committed to a range of actions including: ensuring epilepsy reviews are included in Annual Health Checks (AHCs), improving epilepsy clinics, and sharing details of specialist training in epilepsy nursing to drive improvements and overcome barriers in specialist hospital and community care settings.

A system-wide review of epilepsy services and support

Over winter 2022/2023, 11 of the region's ICSs identified a senior lead to drive and oversee a review of their commissioning and delivery of epilepsy services for people of all ages with a learning disability and autistic people.

The ICSs applied a tailored Learning Disability and Epilepsy Benchmarking Tool (developed by Epilepsy Action) which enables benchmarking and collective reviewing to help compare services against ideal standards

The Midlands team ran workshops and informal 'drop-in clinics' to support the leads with the benchmarking. ICSs were encouraged to engage people with lived experience and other stakeholders in the exercise including families, carers, community teams, neurologists, epilepsy nurses, social care staff, and providers.

The profile of epilepsy in each ICS was raised through this process and some systems have directed leadership and resources specifically for epilepsy. New epilepsy nurse posts have also been appointed. The insights from the benchmarking were shared regionally and used to highlight gaps in service, reflect on opportunities to improve and to plan future epilepsy services.

A new epilepsy advisory group

The Midlands epilepsy programme has also established a regional advisory group which has been instrumental in guiding and supporting improvement in epilepsy care and provision in the Midlands. The group includes national experts, national epilepsy charities SUDEP Action and Epilepsy Action, regional commissioners, and providers including learning disability nurses and psychiatrists, epilepsy consultants, specialist epilepsy nurses, and social care representatives.

Lincolnshire – epilepsy benchmarking programme in action

Lincolnshire ICS held two webinars in January 2023 to review the commissioning and delivery of epilepsy services with more than 120 people including student learning disability nurses, providers, and staff from acute trusts, mental health trusts, local authorities and residential and supported living. Everyone involved agreeing to take actions to improve epilepsy care in their area, such as pledging to ask GPs to look at the SUDEP and seizure safety checklist.

The webinars improved links across the systems with many attendees keen to attend future sessions to learn more about SUDEP, cancer, respiratory issues and constipation. The ICB are now ensuring the SUDEP Action risk assessment is available for all GPs and plan to standardise the form for Annual Health Checks across all primary care in Lincolnshire.

> “We were overwhelmed at the response to the epilepsy webinars. Both Clive’s and Caroline’s stories* really helped the attendees to understand the importance of improving epilepsy care in our systems.”
>
> Catherine Keay,
>
> Head of Commissioning [Mental Health, Learning Disabilities & Autism], NHS Lincolnshire ICB.

*Caroline was a woman with a learning disability and epilepsy from Lincolnshire who died from bilateral pneumonia and COVID-19.

Action from learning in 2022/23: changing how we work

Integrated care systems (ICSs) in action

Making change happen in Birmingham and Solihull

Birmingham and Solihull ICS (BSOL) in partnership with commissioners, experts with a learning disability and autistic people, self-advocacy groups and other stakeholders, launched a three-year public facing strategy for LeDeR in 2022. This aims to improve the experiences in health services for people with a learning disability and autistic people.

The strategy embeds learning from LeDeR into all aspects of the local system and is based on over 500 recommendations from more than 200 local LeDeR reviews. It comprises 20 priority areas for change which all the partners identified together.

Improvements to coordinated care have already been made against these priorities[19] by strategy partners including:

- Midland Mencap after an audit at University Hospitals Birmingham discovered that only 15 of the 300 people with a learning disability or autistic people who were hospitalised in Birmingham in 2022 had a hospital passport, prioritised producing these. The passports share a person's likes and dislikes with staff– helping to break down barriers in communication. They have helped produce more than 100 passports so far.
- Health and social care commissioners at Birmingham City Council helped to share the learning from the success of the hospital passports scheme and encouraged over 1000 providers (e.g., care homes) to ensure their residents have them.
- Commissioners –also changed their approach to monitoring providers, embedding LeDeR learning in their monitoring and quality assurance – for example by providing training and examples to providers of what good quality care should look like. They can also penalise a provider through contractual action if it doesn't meet these standards.

The BSOL LeDeR team share knowledge across social work teams, so that annual health and social care reviews fully consider all aspects of a person's wellbeing, and they work strategically with social care colleagues and with providers to embed LeDeR. The team can raise any issues to the commissioners which informs the quality monitoring of providers with urgent action where needed, giving a provider a timeframe to respond with any necessary actions required.

Reinforcing the strategy is conducted through:

[19] Birmingham and Solihull ICS: Annual LeDeR Report 2021-2022 (Page 20).

Formal governance groups and regular meetings including a monthly LeDeR review oversight panel with representatives from the council, Mencap, self-advocacy services, primary care, acute care, specialist learning disability teams and others who openly discuss the changes they can feed into their organisations.

The Action Learning Group in BSOL which is also reinforcing the 20 priorities through training in GP practices, at day centres and at specific events. The strategy group are asking everyone involved if it is working and, as a result, and strategy partners are feeling more empowered to advocate for their members and call for changes, based on the 20 priorities and a clear understanding of the standards that everyone should expect.

Capturing change:

BSOL LeDeR has funded a 'capturing change' project, contracting Solihull Action through Advocacy, Midland Mencap and Experts by Experience Solihull CIC to work together over the next 3 years to listen to feedback on how the strategy is working from people with lived experience, families, carers and individuals.

Improving standards across all NHS services within priority groups

People with a learning disability and autistic people have been more formally recognised as priority groups across all areas of the NHS in recent years. Learning from LeDeR is enabling us to embed these priority groups in all our services for individuals. In 2022/23 we worked strategically to improve standards in our systems, emphasising people with a learning disability and autistic people at the heart of our work. These include improvements in the following four areas:

1. Benchmarking NHS Trusts

In 2018 NHS England published four learning disability improvement standards to help NHS Trusts improve the quality of care they provide people with a learning disability and autistic people. These were co-produced by people with a learning disability and families and are based on respecting and protecting rights, inclusion and engagement, the workforce, and specialist services.

To support Trusts to make improvements NHS England commissioned an annual national benchmarking programme which involves asking NHS staff, people who use NHS services and families/carers about how services are doing, so they can identify what they do well and where they need to do better.

In 2022/23 we added questions to specifically ask Trusts how learning from LeDeR has been applied in the organisation and what service improvements have been made as a result.

The findings are published on the NHS Benchmarking Network and in 2021 to 2022 showed: People accessing trusts with a learning disability liaison service reported better experiences, improvements in inclusion and engagement with people with a learning disability, autistic people and their families, NHS trusts of all types reported greater availability of learning disability and autism awareness training, and there are more staff providing specialist services in trusts and in the community.

2. **Core20PLUS5** People with a learning disability and autistic people are now specifically included as priority groups in Core20PLUS5 – a new NHS England approach to reducing healthcare inequalities.

Core20PLUS5 defines a target population – the 'Core20' – that is, the most deprived 20% of the national population identified by the national Index of Multiple Deprivation (IMD), plus specific population groups including minority ethnic groups, inclusion health groups, and now 'people with a learning disability and people who are autistic'. The '5' in refers to the five clinical areas of focus for accelerated improvement including severe mental illness, early cancer diagnosis, and respiratory diseases. ICBs must ensure that people with a learning disability and autistic people are considered when tackling local health inequalities.

3. Learning disability, autism and NHS operational priorities for 2023/24

NHS operational planning and contracting guidance for ICBs for 2023/24 gives details of the health priorities for the year ahead. The guidance reconfirms the ongoing need to recover core NHS services and improve productivity, making progress in delivering the key NHS Long Term Plan ambitions and continuing to transform the NHS for the future.

The specific objectives to improve services for people with a learning disability and autistic people are to:

- ensure 75% of people aged over 14 on GP learning disability registers receive an annual health check and health action plan by March 2024
- reduce reliance on inpatient mental health care, (while also improving the quality of inpatient care) so that by March 2024 fewer adults and children with a learning disability and autistic people are cared for in an inpatient unit
- continue to prevent and address health inequalities and deliver on the Core20PLUS5 approach.

4. The NHS Standard Contract for 2023/24

There is an increased focus on people with a learning disability and autistic people in the new NHS Standard Contract which runs from 1 April 2023 to 31 March 2024. This contract is used when any NHS service is commissioned (except primary care). Some of the additions to the contract were based on recommendations from the LeDeR team and include:

- guidance on end of life care now also including the Universal Principles for Advance Care Planning (Published in March 2022) and guidance on DNACPR
- the requirement for providers to report the death of people with a learning disability and autistic people who died while they were known to their services using the LeDeR platform.

Annual health checks (AHCs)

An Annual Health Check (AHC) is a regular opportunity to promote a healthy lifestyle, support wellbeing, and enable early access to additional healthcare support if an individual needs this. It is important that everyone over the age of 14 who is on their doctor's learning disability register has an AHC as it can also help spot the early signs of illnesses such as cancer and diabetes, or respiratory and heart issues. This can lead to earlier treatment and better health outcomes.

An AHC is also an opportunity to discuss vaccinations, screening, manage and monitor known health conditions such as epilepsy or dysphagia (swallowing difficulties), and to discuss Do Not Attempt Cardiopulmonary Resuscitation decisions. A doctor, pharmacist, nurse or healthcare assistant can conduct an AHC, with final oversight from the GP. Every AHC should be supported by a health action plan (HAP) for the individual.

In our work to drive the uptake and quality of AHCs in 2022/23 we:

Led events, webinars or gave presentations:

- about the importance of and best practice in AHCs and about the learning disability register for GPs. We also established a community of practice to share good practice including how AHCs can be delivered by different practice staff to reduce demands on GPs. Over 800 people attended and events continue to run throughout 2023. The guidance on best practice in AHCs is available on the FutureNHS platform (For NHS staff).
- on the importance of AHCs in reducing health inequalities for people with a learning disability and autistic people to Academic Health Science Networks (AHSNs), provider forums, regional health inequality meetings and at BILD’s GOLD conference on ageing well

Produced new resources and reports including:

- a film portraying Charlotte’s AHC and Health Action Plan (HAP) which is easily accessible and can be used as both a training resource and to help people understand what a good quality AHC should look like
- a report from the National Autistic Society who we commissioned to engage harder to reach groups – including homeless people, transgender people – and ask how to support them with AHCs.

- a new document for parents/carers (including a plain English and easy read versions) to support conversations with GPs about adding children and young people to the register as part of a primary care review on the quality and improvement of AHCs and the register. (To be published in late 2023)

Worked nationally and regionally to:

- include AHCs in local health policies where appropriate and to update aspects of 2023/24 contracts to ensure AHCs are included –for example in the NHS Standard Contract for people in inpatient settings, and the Specialist Commissioning Service Specification to include AHCs for those in private hospitals. The primary care contract continues to include AHCs - with a greater emphasis on ethnicity recording and HAPs
- support several regional exemplar sites working to improve access to and uptake of AHCs.

Autism specific annual health checks

The NHS Long Term Plan said that by March 2024 at least 75% of people aged 14 and over on a GP learning disability register should receive an AHC. However, 70% of autistic people[20] do not have a learning disability, autistic people are more likely to experience poor health[21], and the mortality rate is 1.3 times higher in autistic people than the general population[22]. Some health services and professionals could do more to provide autistic people with sufficiently adapted and supportive care.

A new pilot

The NHS long term plan also said that NHS England will, 'pilot the introduction of a specific health check for autistic people, and if successful, extend it more widely'. We have now funded four NHS regions to deliver this pilot - the East of England, North East and Yorkshire, London, and the Midlands. Primary care practices in these areas delivered their first health checks for autistic people in January 2023 and are conducting around 480 autism specific health checks this year.

Every stage of the process is providing information on the practicalities of both offering and implementing specific checks for autistic people e.g. about how GP practices can accurately identify all their autistic patients A full evaluation will collate all the learning and identify any themes that have arisen.

A randomised controlled trial (RCT)

[20] FutureNHS: (Autism Strategy Dashboards) – This is an internal workspace for NHS colleagues.

[21] *Weir, E at al. Increased prevalence of non-communicable physical health conditions among autistic adults. Autism; 9 Sept 2020*

Although the process and ethos of the health checks for autistic people is similar to those for people with a learning disability, the autism specific health check is based on a template co-produced by Newcastle University who were commissioned by NHS England and Autistica to develop it.

The University was also commissioned to test for clinical outcomes for autistic people as part of a randomised controlled trial (RCT). An RCT typically compares a new treatment with an existing standard of care and in this case to identify previously unmet clinical needs. The bespoke template includes holistic questions around medication, mental and physical health problems, eating and sleeping. It aims to reinforce the importance of considering an autistic person's sensory needs, for example around reducing noise or limiting touch, raise awareness of the need for reasonable adjustments and ultimately improve access to mainstream healthcare. The RCT will report in 2024.

In Brief - other annual health check improvements

The North West

Greater Manchester ICP worked with Manchester People First - a self-advocacy group for adults with a learning disability and AJs Academy - an activity resource day centre which supports individuals who have a learning disability and their families, to co-produce easy read documents to support the AHC Process. They also co-produced a 'patient journey map' which will be used to develop quality measures for AHCs in 2023/24 to deliver a clear, consistent approach to AHCs.

North East and Yorkshire

NHS England funded pilot approaches in annual health checks. One of these resulted in the Bridlington Learning Disability and Wellbeing Hub, which opened in late 2022 is based in the Bridlington Primary Care Network. The community learning disability team have created a series of videos around AHCs, describing their holistic approach to wellbeing through social prescribing. Other PCNs in their ICB are now looking to use this model.

South Yorkshire ICB (Sheffield Place) asked all their GP practices to prioritise AHCs for people who did not receive a check in 2021/22. They also commissioned an outreach initiative led by Sheffield Mencap and Gateway (SMG) where SMG supported hard to reach patients to attend their AHC. Several surgeries were also involved in a pilot led by Foundry Primary Care Network to use Care Coordinators and Physician Associate roles in GP practices to conduct AHCs. As a result of these and other efforts, 3,382 health checks were recorded in Sheffield in 2022/23 - meaning 889 more people[23] received an AHC than in the previous year

[23] Based on 2022- 2023 data for Sheffield, resulting in an AHC uptake at end of March 2023 of 84.8% (against a 75% target).

"As a very busy practice we don't always have the time or resources to try and reach out, but with your help we've been able to engage with more patients and ensure they have a yearly health check. Many of our patients ha---ve benefited from your support by accompanying them to appointments they otherwise may not attend or [by your] offering advice and guidance. Your help has been invaluable to our practice and our patients."

A GP practice thanks Sheffield Mencap and Gateway for their support with annual health checks.

An updated toolkit for London

The AHC Toolkit for London, a comprehensive guide for GPs to support the completion of good quality AHCs, which was first published in late 2021, has been reviewed, refreshed, and republished. It is now available on the FutureNHS site (for NHS staff) and has been circulated to GPs and PCNs across London.

Children and young people in the Midlands

The Midlands Learning Disability, Autism and SEND Team have worked together with partners across the Midlands to improve the uptake and experience of AHCs among children and young people aged 14 and over with a learning disability. LeDeR reviews show take up of AHCs is lower in younger people.

A new Midlands Regional AHC Improvement Framework has been developed using intelligence from events attended by health and social care partners. It outlines a series of five priorities and goals, the actions required to achieve them, and examples of good practice in AHCs for children and young people. One action will embed AHCs into the education, health and care plan (EHCP) process while another suggests local authorities and health commissioners work together to ensure a smooth transition for young people to adult services.

The framework has been circulated widely across all systems, GP practices, SEND boards and learning disability and autism networks in the Midlands - and the region is already seeing improvements. By December 2022, over 500 more AHCs were completed for children and young people compared to Dec 2021.

Race, Religion, Ethnicity and Culture

LeDeR reports show that people from a minority ethnic group with a learning disability have even poorer outcomes than other people with a learning disability.

In response NHS England has commissioned a series of projects we are either leading or supporting. These include:

- improving ethnicity recording
- tackling health inequalities
- focused LeDeR reviews
- anti-racism initiatives
- intersectionality training.

Recording ethnicity

We worked to amend the (Investment and Impact Fund) IIF indicator for learning disability in AHCs to include a requirement to record ethnicity for people with a learning disability. This has now been included from April 2023 and outlined in the new GP contract letter which was published in March 2023.

Tackling the barriers that drive health inequality

We commissioned work from the NHS Race and Health Observatory to help us to better understand the reasons behind health inequalities faced by people with a learning disability who are from a minority ethnic background and to suggest practical solutions to these barriers that the NHS and our partners could take.

Their report, 'We deserve better: Ethnic minorities with a learning disability and access to healthcare' published in July 2023 and went to the July meeting of the NHS England Board, was produced with the University of Central Lancashire (UCLan), partner organisations, and a working group of people with lived experience. It makes a number of recommendations at ICB, regional and national level, as well as making recommendations for those commissioning and conducting research around health and care. The main recommendations include:

- the development of future health and social care policies should, as standard, include advice emphasising coproduction approaches to tackling health inequalities experienced by people with a learning disability from ethnic minority backgrounds
- improving the completeness and accuracy of ethnicity coding of people with a learning disability across all NHS and care providers
- LeDeR reviewers should ensure that they accurately record in the LeDeR review the ethnicity of the person whose death they are reviewing

- specific research in under-represented groups such as asylum seekers, the Jewish community and Irish Travellers should be commissioned

NHS England is working with partners to develop an action plan to address the recommendations which will go to a meeting of the NHS England board in Autumn 2023. The work will build on the requirement introduced 2023 for GPs to record ethnicity as part of the learning disability annual health check.

Focused LeDeR reviews

A 'focused' LeDeR review is conducted into the death of every person with a learning disability from a minority ethnic group notified the system. Once a death is reported to LeDeR a reviewer conducts an 'initial' LeDeR review by talking to family, carers and professionals involved in the person's care. A focused review looks in more detail at the person's life.

ICBs use this evidence to drive service improvements in health and social care for people from minority ethnic groups in their area. In addition, every ICB has a named lead for minority ethnic groups on their LeDeR governance group.

Intersectionality training

NHS England has also delivered a 'train the trainer' programme to support LeDeR reviewers and local systems to consider 'intersectionality' – that is how the different aspects of someone's identity, for example race, culture and religion, can overlap or 'intersect' with their learning disability or autism and significantly increase health inequalities in the quality of care and support provided to the person during their life.

More than 130 people from ICBs across England were trained by January 2023 as LeDeR intersectionality trainers which will enable them to cascade their knowledge across local systems so that their local workforce is trained. This will equip staff to consider issues of intersectionality as an essential part of reviews.

The training includes three films on intersectionality which feature conversations with people with a learning disability and autism and their families. Exploring issues of culture, race, ethnicity, religion and experience of care, the films have been shared extensively across all mental health trusts in the Mental Health Learning Disability bulletin and across Learning Disability staff.

Feedback from the delegates who attended the intersectionality training so far has been extremely positive:

> "It really made me think about power and inequality and how I can ask questions in a curious and respectful way."

In the films, Adam and his father Jonathan discuss Judaism and how it is an essential part of their identity.

Jide and his mother Mary discuss their Christian faith, Jide's Nigerian heritage, and racism.

Daniya and her mum Ayesha discuss their culture, their Islamic faith and challenges they face.

The 'Equal Treatment' Project

An anti-racism initiative funded by NHS England and led by Learning Disability England (LDE), saw seminars, workshops and training delivered throughout 2022. The Equal Treatment project challenges racism and health inequalities through strengthening self-advocacy and peer support. LDE worked in partnership with the charities Changing Our Lives, Contact, and IncludeMeToo.

The project aims to:

- strengthen self-advocacy and parent/carer organisations' work with people with a learning disability from minority ethnic groups and their families
- increase the confidence of local organisations led by people from minority ethnic groups in working with people with a learning disability and their families when tackling health inequalities
- link these efforts with wider initiatives to reduce premature mortality and health inequalities.

So far, three distinct strands of work have been delivered in these areas including:

Strand 1

Changing Our Lives, which aims to reframe how society views mental health and disability, delivered training to 10 organisations which included three sessions in person with 38 self-advocates and online training workshops for 20 senior staff from the 10 organisations. Several resources including short films, images and resource explainers were developed as part of this work.

Strand 2

Contact, for families with disabled children, co-developed and delivered a three workshop training programme for 13 parent/carer forums based on the participating organisations' needs. The training covered understanding representation and inclusion, intersectional disadvantage, identification of information gaps and action planning.

Strand 3

Seminars run by IncludeMeToo, a charity for children and young people with a disability and their families, aimed to raise awareness among wider community organisations of the racism and inequalities that could be faced by people with a learning disability from minority ethnic groups. Their seminars shared knowledge, challenged assumptions, and planned actions to tackle inequalities.

Finally, LDE hosted a sharing session in September 2022 which was attended by more than 50 delegates. All three work strands shared their key learning from their projects. The recording of the session is available here.

Feedback from this session demonstrated an appetite to continue the discussions, training and ultimate work in this area.

Leadership training for people with a learning disability and autistic people

NHS England has funded a project and survey from Learning Disability England which will help us and our partners to assess what leadership training opportunities there are for people with a learning disability and autistic people, who are from a minority ethnic group. We also want to identify and understand how the experiences of ethnic minority people, intersectionality, anti-racism, and inclusive practice are included in these programmes.

When LDE worked with people and organisations as part of the Equal Treatment and Working Together to get the job done projects they heard from some people that leadership training does not always include people from minority ethnic groups with a learning disability or autistic people. They also learnt that training about different people's experiences and anti-racism practice is not always accessible.

The LDE survey which was completed in spring 2023 asked what leadership or similar training there is aimed at or led by people with a learning disability or autistic people. The results from the survey and project will help us to understand current training opportunities and will see the production of an accessible report summarising improvement ideas.

Improving access to health in minority ethnic groups

In 2022 NHS Bristol, North Somerset and South Gloucestershire (BNSSG) ICB commissioned Autism Independence to explore the lived experiences of accessing health services among black and other minority ethnic groups where there is a young person aged over 16 in the family who is autistic or has a learning disability.

The charity worked with 42 families before presenting their findings in January 2023. They were joined by the families at the launch and enjoyed a celebratory meal afterwards with the Somali community. The report was also later presented at the South West's regional Health Inequalities Improvement Group.

The report found that there was poor health engagement with AHCs, screening programmes and health appointments. The ICS is now looking to establish two 'care navigator' or bridging worker roles which will work with families where English is not their first language. The postholders will provide support and signpost parents and young people with a learning disability and autistic young people from minority ethnic groups to better access health services. This two-year pilot scheme will see care navigators recruited from minority ethnic groups and, if successful, it is proposed that the posts will become permanent.

BNSSG is also funding training which will be developed with community leaders to help improve access to health services among minority ethnic groups where there is an autistic person or a person with a learning disability in the family.

End of life care and advance care planning

LeDeR reviews have highlighted some issues for people with a learning disability and their families around informed choices for end of life care and decisions around any potential Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) recommendations. The 2021 LeDeR Report[24] indicates that there were still a significant percentage of cases where good practice in DNACPR decision making was not demonstrated. NHS England has co-produced a number of resources and a national framework focused on ensuring equality in access to end of life care and palliative care to tackle these inequalities for people with a learning disability.

The pandemic and the Care Quality Commission (CQC) report Protect, respect, connect – decisions about living and dying well during COVID-19, reinforced that people with a learning disability must be centre stage in making their own end of life plans. NHS England and partner organisations developed universal principles for advance care planning in March 2022 to support this, by making recommendations including the use of an ‘advance care plan’. These plans should be personalised - developed with the person and/or their family and carers - and should be sharable and clearly document what matters to the person, their preferences and decisions about future care and treatment.

NHS England also worked with NHS Digital (now part of NHS England) to develop a code on the clinical record that specifically identifies that a conversation has taken place every year with a person with a learning disability and/or their family and carers about DNACPR. This practise started in April 2022 and means that GPs are now expected to add a SNOMED CT* code to a person’s clinical record during their annual health check to confirm that a conversation has taken place about DNACPR. In future we will be able to have better confidence that a DNACPR has been put in place appropriately. *A SNOMED CT (Systematized Nomenclature of Medicine Clinical Terms) code is a shared language used in electronic health records enabling information to be shared more easily between them.

In March 2023 we sent a letter to clinical leads and chief nurses in ICBs, medical directors and executive directors of nursing in NHS Foundation Trusts, and all GPs and primary care nurses to remind them and their systems of the importance of the appropriate use of DNACPR decisions for people with a learning disability and autistic people. This also stressed the importance of implementing the Universal principles for advance care planning and ensuring that DNACPR decisions for people with a learning disability and autistic people are appropriate, are made on an individual basis and that conversations are reasonably adjusted.

---

[24] LeDeR Annual Report 2021: King’s College London et al. (Page 26) https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf

Regional projects to improve future planning

Many self-advocacy groups working with people with a learning disability are also encouraging their members to have good quality conversations about their death, while they are well, so they are better informed and can feel confident that their wishes will be considered and that they will have a greater sense of control over their ability to live and die well.

NHS England has funded three self-advocacy groups - People First Merseyside, Inclusion North and SpeakUp - to create distinct projects in advance care planning which will strengthen our efforts in this area. The projects will be delivered by the end of 2023 and will create a collection of easy read materials, workshop plans, bespoke training, and films. These resources and any learning from developing them will be cascaded by NHS England and our partners.

Informing choices on DNACPR in the North West

People First Merseyside are using their funding from NHS England to create national resources to empower people with a learning disability and their families to make informed choices around DNACPR in any future end of life care.

This initiative will build on the success of their Dignity and Voices in Dying project 'DAVID' which was named in honour of a service member who sadly died. David had no family and the group realised they did not know what his final wishes were so People First's members decided to do some work around planning for their own end of life choices, and the DAVID project was created.

DAVID aims to bring members and their families together in 'death cafés' - informal settings where they discuss the subject of death and are empowered to plan ahead before they face any crisis point in their health. This enables members to be proactive in informing their choices around making a living will, power of attorney, organ donation and even the music they want at their funeral.

Members are also working with 'Task and Finish' groups to:

- create a resource pack for will writing with information for both people with a learning disability and families/carers
- collate materials for an 'organ donation resource pack' they are producing
- try out activities for potential inclusion in the above packs and seek feedback at the cafés.

The DNACPR work will see the team and People First members behind the DAVID initiative create a new film, produce a resource booklet, and deliver awareness raising sessions across the North West on DNACPR issues. The DNACPR work will be delivered later in 2023 and the resources made widely available.

End of life conversations in death cafés

Inclusion North has used the NHS England funding to support improvements in end of life conversations among people with a learning disability, autistic people and their families and by:

- raising awareness of good practice with health professionals across the North East, Yorkshire and Humber
- developing resources to support people with a learning disability, autistic people and their families to get more comfortable talking about death, dying and making plans for the future.

They are working with their Stop People Dying Too Young Group and local palliative care professionals to ensure that experts lead this work.

To support people with a learning disability, autistic people and their families to get more comfortable talking about death, dying and making plans for the future they are creating resources which will be cascaded to support others to run facilitated conversations at 'death cafés'.

Although the name 'death cafés' may seem unpalatable, the group feel that it reflects the need for the language around death and dying to be straightforward - by using the words 'death' and 'dying' and not euphemisms which can be confusing such as saying someone is 'lost' or has 'passed away.' The sessions will include supportive guidance and tackle difficult issues in fun and gentle ways.

People with a learning disability, autistic people and family carers are also deciding the content in these café sessions – choosing the topics, as well as making a film which will discuss choices and expression of their wishes earlier in their lives.

The project will create new resources by Autumn 2023 for health professionals which will be available on their site, and will signpost to the end of life pathway and existing end of life guidance for people who have a learning disability. The 'Stop' group are also making a video/short film for health professionals, emphasising the individual at the heart of these discussions, as people felt that their rights were being ignored. The group want to ensure that the film reminds professionals:

- Not to assume that a person does not have the capacity to make decisions
- To talk to them
- To talk to their family
- See them as a person
- To use the Deciding Right materials – an initiative for making care decisions in advance in a shared partnership between the professional and the child, young person or adult, carer or parent
- To ensure their NHS Trust is aware of the Deciding Right materials.

The 'Stop' group will lead on delivering the death café materials, while campaigns like Dying Matters Week will help to raise the awareness of both the new resources and the voices of people with a learning disability and autism on end of life discussions. The resources for NHS staff will also be cascaded through internal training across the North and via NHS England networks.

Training in end of life decisions

Speakup have used the funding they received from NHS England to co-produce training and supporting materials in South Yorkshire for use with people with a learning disability, autistic people and their families. The materials will facilitate two sessions in each of the following areas: DNACPR, making difficult decisions, and advance decision making. The training started in October 2022, will be completed in late 2023 and is using the ECHO training platform which provides professional training for the care industry.

All the materials produced, including an easy read and a film about bereavement, will be made available through the Speakup website and shared via the ECHO super-hub, so anyone with access to this in England can also deliver the training. The work is being supported by South Yorkshire ICB.

Mental Capacity

The Mental Capacity Act 2005 (MCA) provides a legal framework to protect people who lack the mental capacity to make their own decisions about their care and treatment and to help them take part, as much as possible, in decisions that affect them. It also covers people who have capacity and want to make preparations for a time when they might not. Compliance with MCA is a consistent theme in LeDeR reviews.

Informed decisions on vaccination in London

In October 2022, the safeguarding and learning disability and autism teams in the London region together published two documents to support healthcare professionals in respiratory networks and the over 1,150 GP practices in the regions who undertake AHCs on their approach to decision making about flu and COVID-19 vaccines where an individual lacks capacity. The guidance reiterated that all practicable steps should be taken to support the person with a learning disability to make a decision on vaccination for themselves by helping to inform the individual in a way that works for them about:
what the vaccine is, how it works and to understand what could happen if they choose not to have the vaccine – for example how it could prevent people from becoming seriously ill with the flu virus or COVID-19

- any potential side-effects
- the process involved in having the vaccine.

The two resources included guidance on providing information to family members and/or carers where they were responsible for any decisions, and if not, where 'best interests' decisions must be made. This is a decision on whether it is in the person's best interests to have a vaccine at that particular time, based on all available information and any risks to the person themselves, other residents or staff. The resources provided links to COVID-19 vaccination guidance for healthcare workers from the UK Health Security Agency (updated in October 2022), guidance on protecting yourself from the flu, and easy read COVID guides.

They also provided information on the Mental Capacity Toolkit – a comprehensive guide to support health and care professionals by the Burdett Trust for Nursing (a charitable trust which makes grants in support of nurse-led projects).

Reasonable adjustments

Under the Equality Act 2010 organisations have a legal duty to ensure that their services are as accessible to people with a disability as they are to anyone else – by making ‘reasonable adjustments’ where these are needed.

Reasonable adjustments for someone with a learning disability or an autistic person could include longer appointments, providing easy read information or having the support of a carer. They will vary from person to person.

The introduction of the reasonable adjustment digital flag (RADF)

For optimum care to be delivered, all reasonable adjustments need to be identified, recorded, and shared across the NHS and social care. A new ‘reasonable adjustment digital flag’ in a patient’s records will do just that. The flag will ensure staff know if a patient has a learning disability or is autistic and indicates what reasonable adjustments are needed.

The digital flag has been created on the NHS Spine. Healthcare professionals and administrative staff with the appropriate security permissions can identify, record, view, add or remove information from the flag, using the National Care Records Service (NCRS). The digital flag is currently being tested in live clinical systems and will be rolled out by 2024. It will be accompanied by an Information Standard, mandating the use of the digital flag, across all health and publicly-funded social care services, across all ages, by April 2024. The reasonable adjustment digital flag will be supported by a communications campaign, staff training and an implementation plan, recognising the significant cultural change this represents.

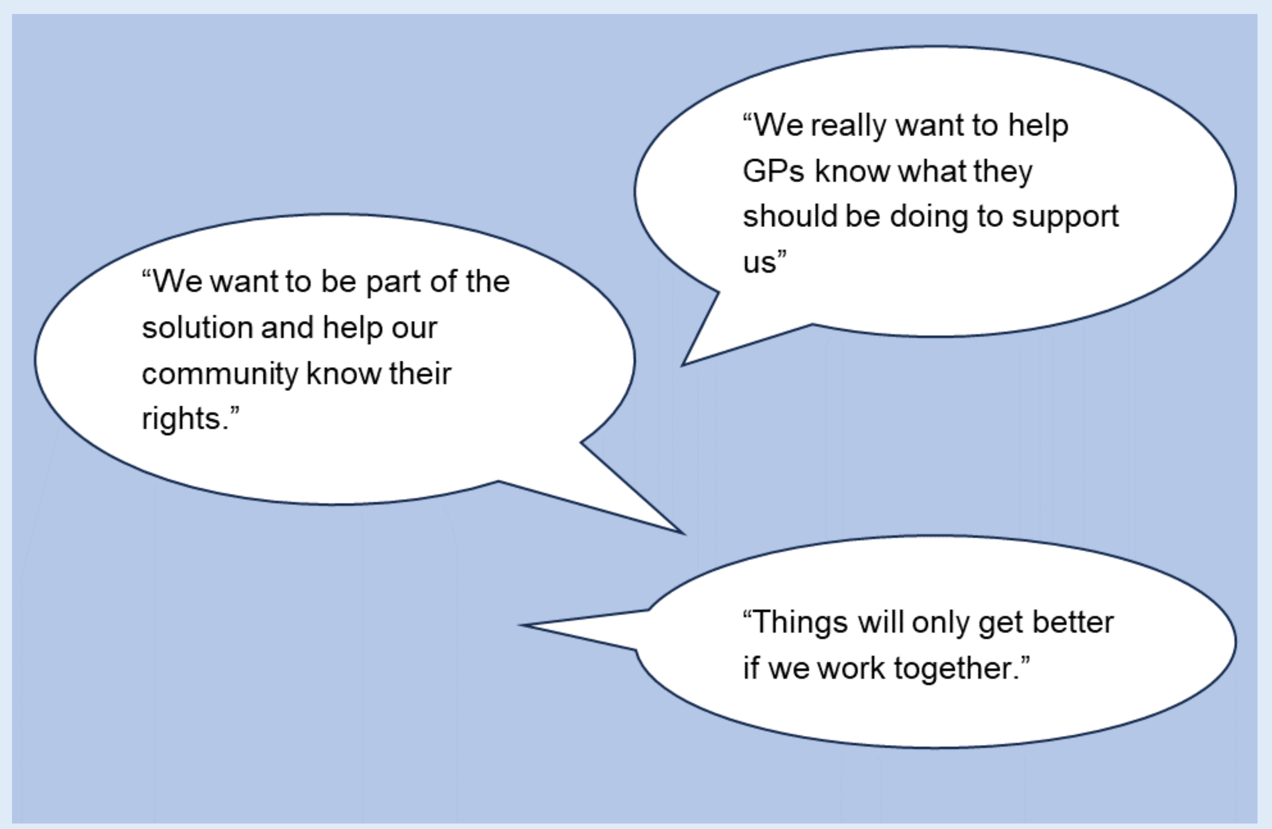
We have published an Information Standards Notice for the RADF under section 250 of the Health and Social Care Act 2012. This provides an overview of scope and implementation

Reasonable adjustment letters for GPs

Pathways Associates, a community interest company, worked in partnership with the learning disability team in Bury ICS to produce a letter in easy read format which GP practices can send to their patients who have a learning disability and autistic patients. The letter is based on learning from LeDeR and was created to help improve the quality of reasonable adjustments in Bury, Greater Manchester.

It provides a checklist of potential reasonable adjustments including longer appointments, large print resources, and easy read invitations. Patients or their family/carer can also add details of other reasonable adjustments which a GP practice could then put into place.

The North West Regional Forum, a self-advocacy group, also wanted to help improve the reasonable adjustments made for people with a learning disability and autistic people in the region and so teamed up with Bury People First self-advocacy group, to produce a letter that people with a learning disability can complete and give to their GP practice. Both groups felt they wanted to support their community to be more proactive in informing GPs of their needs.



Group members explain their reasonable adjustments letters.

Both resources have been distributed by the Learning Disability Partnership Board in Bury whose members include people with a learning disability, carers, local authority, NHS and service providers. Early adopters of the 'reasonable adjustments digital flag' project have also shared the resources with other early adopters. They have all found the letters helpful and easy to roll out in their areas.

Bury Local Authority added a link to the easy read letter for GP practices in their Care Act assessment form. They have also applied learning from LeDeR and others to improve the form, increase take up of AHCs, and promote information sharing and access to health. Newly completed letters will be shared with GPs.

Sensory friendly resource pack

NHS England's National Autism Team published a new sensory friendly resource pack in October 2022. The resource initially aimed to improve the environment for autistic people in mental health inpatient settings, however it can be used in any health setting, and is aimed at all health professionals working with autistic people.

Recent studies suggest sensory sensitivities are experienced by over 90% of autistic children and can persist into adulthood[26]. There are three categories of sensory sensitivities:

- hyper-sensitivity – extreme over-reactivity to sensory input
- hypo-sensitivity – extreme under-reactivity to sensory input
- sensory-seeking – unusual interest in aspects of the sensory environment.

The pack explains how non-autism-friendly environments could impact on autistic people and hamper their recovery before providing a series of ten ward principles with suggestions on how to make a hospital ward sensory friendly. These include:

- working with autistic people to review the environment
- creating a predictable environment and reducing noise
- ensuring training is given to anyone whose role could impact on the autistic person's experience – including cooks, cleaners, agency staff and anyone caring for the person
- considering the impact of lighting, smells, touch and texture in the personal care needs of individuals, for example, around textures such as towels
- making and regularly reviewing decisions based on an individual's needs.

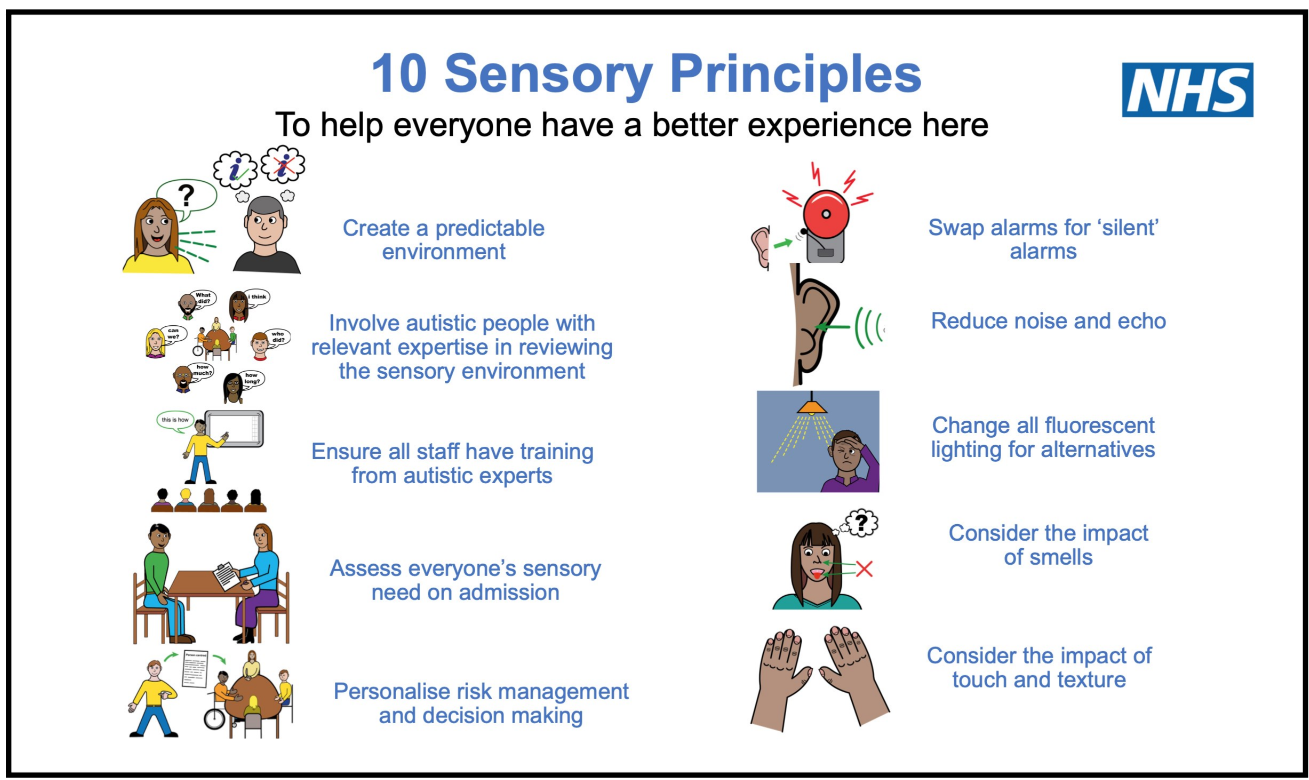
---

[26] Baranek GT, David FJ, Poe MD, Stone WL, Watson LR (2006) Sensory Experiences Questionnaire: discriminating sensory features in young children with autism, developmental delays, and typical development. *Journal of Child Psychology and Psychiatry*, *47(6)*, 591-601.

And Leekam SR, Nieto C, Libby SJ, et al (2007) Describing the sensory abnormalities of children and adults with autism. *Journal of Autism and Developmental Disorders*, 37*(5)*, 894–910.

NHSE also commissioned a re-write of the Green Light Toolkit, which was first published in 2004 to help mental health services to audit and improve their service. The new version of the Toolkit (2022) has been distributed with the new sensory pack and emphasises the importance of creating accessible environments for people with sensory differences. It also has a wider choice of questions in the survey. Both resources have been shared with every ICB in England.

A new short film has been produced to describe the sensory friendly resource pack to ICSs along with a 10 sensory principles poster which lists some of the actions that local systems can adopt to help improve patients' experience.



The '10 Sensory Principles' poster.

Making emergency departments accessible in Leeds

In 2021 the Learning Disability and Autism team at Leeds Teaching Hospitals NHS Trust conducted an audit of emergency departments. The team asked the area's Autism Reference Group - a forum for autistic adults to have their say on services and support in Leeds - to share their experiences of the emergency department (ED). The feedback established that although some people had a positive experience, many found the ED environment stressful. For example, it could be overstimulating – increasing stress levels, leading some people to discharge themselves or reluctance among some patients to attend.

The team successfully applied for an innovations grant from the Leeds Hospitals Charity to fund the production of 350 'care bags' which were designed with people with lived experience of having a learning disability or being autistic. Over 200 bags have now been distributed in the EDs in the trust since April 2022 to all patients with a known diagnosis of learning disability or autism. The bags contain items to help patients to manage in the busy waiting room in the ED, to the assessment area, during investigations and ultimately to a hospital ward if they need to be admitted.

The care bags contain:

- Easy read information about the department
- The Friends and Family Test
- Sensory and distraction items - ear defenders, an eye mask, a fidget gadget, a stress ball, an adult colouring book and pencils, and a chew ring
- An easy read evaluation form.

The Learning Disability and Autism team has trained nearly 300 staff working across all specialities in the emergency department in the use of the bags and as a result they have been made aware of 12 inpatients who needed support who they otherwise may not have been notified about. The team have also added new appropriate alerts to the records of over 50 patients and have completed new hospital passports for every appropriate patient.

The bags have proved a big hit with patients, families and staff at the hospitals – so far receiving 98% positive feedback in the ongoing evaluation.

Aaron Senior a lived experience autism advisor with NHS England received one of the bags during a visit to St James's University Hospital and was invited to create a short film about the bags and share the work the hospital are doing. Another patient with autism who spent 10 hours in St James's Hospital ED gave feedback to the hospital that the care bag made a huge difference when she was unwell and helped her to stay at the hospital to get the treatment she needed when she felt she may otherwise have left.

The Trust is now applying for funding to roll it out to all acute admitting areas and not just the emergency departments.

A screenshot from Aaron's film about care bags.

Improving urgent care in London

In April 2022 Urgent Care Plans (now called Universal Care Plans (UCP)) replaced Coordinate my Care. These electronic health records were used across London to share a person's palliative care needs but have now been developed for use as a hospital passport for people with a learning disability and autistic people.

Staff from the Tower Hamlets Learning Disability Service contacted people with a learning disability who are known to the service and have the most complex care needs, asking them/ their carer if they want an UCP and helping to complete one.

UCP forms are completed by health care professions, but future plans will enable the individual and/or their carer to complete them, with a GP or other health professional signing them off. UCPs can be accessed directly by call handlers dealing with 999 calls, the London Ambulance Service, A&E, primary and secondary care, and specialist services e.g. community learning disability services.

The plans include: a person's significant medical history, their wishes and needs, medications, end of life choices, and any reasonable adjustments such as turn off blue lights on an ambulance if an autistic person finds them distressing.

Over 100 Tower Hamlets service users have signed up for a UCP so far and the borough aims to make the UCP become part of the annual health check process. The team have also created a short video about urgent care plans – about why they can be helpful and how to complete them – for link nurses, GPs, and others.

As the UCP template is standardised, a pan-London working group led by London Ambulance Service which includes GP leads, community and hospital learning disability liaison staff, learning disability and autism teams, and LeDeR colleagues, is now developing a more specific template for the UCP for people with a learning disability and autistic people. They have also met with two self-advocacy groups in Enfield for their views on making UCPs more accessible.

Agreement is now in place with the UCP developer, Better, and the pan-London commissioners of the UCP to take these developments forward, with a UCP template that includes specific questions about additional support needed by people with a learning disability or autism, for example, any sensory needs, soft signs of deterioration, and other conditions they may have.

Eliminating the elective care backlog for people with a learning disability

Calderdale and Huddersfield NHS Foundation Trust (CHFT) in West Yorkshire worked to prioritise patients who are more likely to experience health inequalities, including people with a learning disability and autistic people, when they tackled a backlog in elective care.

In 2021 there were 77 patients with a learning disability on a waiting list for treatment at the Trust after spikes in COVID-19 cases saw non-urgent elective treatments cancelled and staff redeployed. CHFT adopted a whole Trust approach – led by a strongly committed leadership team, to ensure priority treatment for people with a learning disability awaiting surgery.

To do this, the Trust adopted a range of actions including:

using data to develop and implement tools to identify patients with a learning disability, understand their experiences and clinical need, and monitor impact of any waiting time. The tools the Trust used included:

- scrutinising information on readmissions, length of hospital stay and mortality for people with a learning disability. This enabled the Trust to target any actions – including prioritising people with a learning disability who were waiting for surgery
- a flagging system within patient records
- a learning disabilities data dashboard
- a data model offering comparisons against the general population
- running a 'deep dive' into patient journeys
- auditing the reasonable adjustments made by the Trust, cancer data and missed appointments.

A consultant nurse for learning disabilities leads the work in the Trust. The Trust has also recruited a health inequalities project manager for learning disabilities. The team meets monthly to monitor the waiting lists to ensure people with a learning disability continue to be prioritised within 18 weeks – addressing LeDeR reports which have highlighted that a third of deaths of people with a learning disability were from treatable medical causes. The Trust has also analysed their waiting list data by deprivation and ethnicity; working to narrow any gaps.

Improving reasonable adjustment services in Wolverhampton

In autumn 2022 nurses in the Learning Disability and Autism Team at The Royal Wolverhampton NHS Trust launched a service improvement programme (SIP) to improve the experiences of people with a learning disability attending the hospital.

Patients on a GP learning disability register have a learning disability 'flag' on their electronic patient record at the hospital. Flagged patients who have an upcoming outpatient appointment will then receive a phone call from a member of staff at one of the 12 clinics across the Trust that they are due to attend, e.g. fracture clinic, urology, ophthalmology. The patient or their family/carers are asked what, if any, reasonable adjustments are needed when they attend the

clinic. The phone call also acts as a reminder to the patient that they have an appointment and staff can reassure nervous patients. These simple adjustments have included:

- doing a practice run so patients can see what is involved in their treatment
- enabling anxious patients to go straight into their allocated appointment or come in through the back entrance
- accommodating patients who have a number of carers
- helping patients to understand any proposed treatment.

The nurses have supported patients through surgery, after general anaesthetics, and attended radiotherapy or chemotherapy sessions. One nurse supported a woman with a learning disability through childbirth while the nursing team also supports patients to understand difficult prognoses.

There has been a significant reduction in the number of patients who 'did not attend' an appointment – from around 26% of patients with a learning disability flag missing appointments, (over double the number of missed appointments compared to people without a flag), to almost zero.

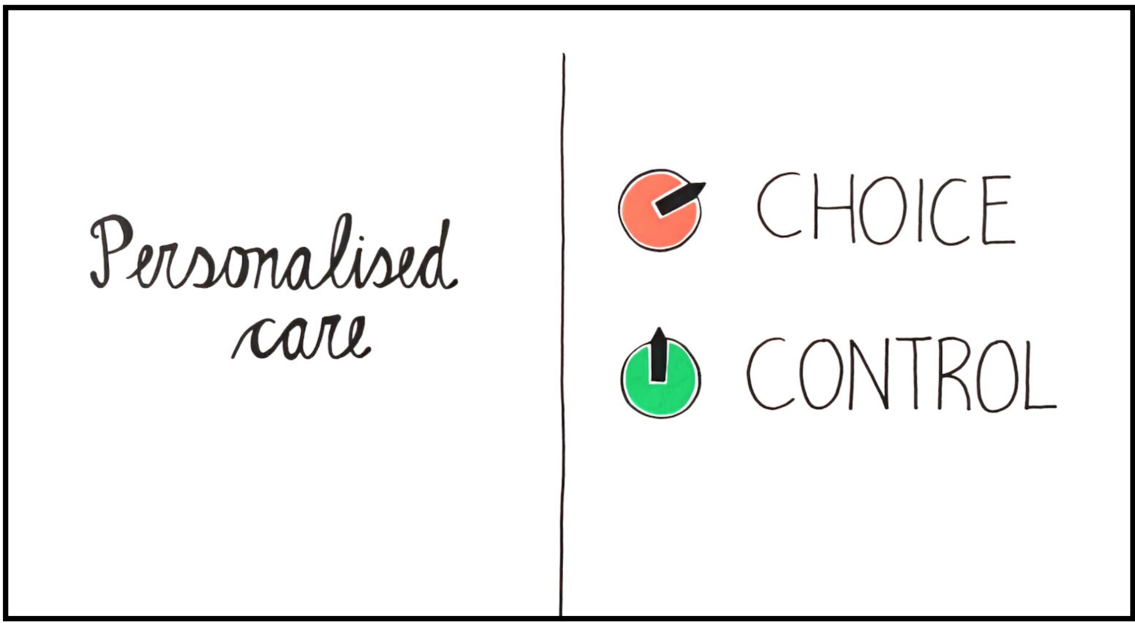
Reasonable adjustments are documented in the patient's electronic record. These records can also be used for inpatients with a learning disability and can be built upon over time – for example by adding a patient's hospital passport with details of their likes and dislikes, or any accessibility issues.

The service improvements are helping over 3000 people on the learning disability register locally and the team are now working to use a similar system of applying reasonable adjustments to over 1000 patients who are identified as being autistic. Patients are experiencing better health outcomes by being able to be seen in a timely manner, appointment slots are not being wasted and patients are having better experiences in their person-centred treatment.

Social prescribing and personal health budgets (PHBs)

The NHS Long Term Plan (2019) included plans to roll out a personalised care model across the country, to expand the choice people have in their mental and physical health care and control over it. One aspect of this model includes a social prescribing offer, which widens and diversifies the range of support available to people. Link workers in PCNs work with people to develop tailored plans and connect them to local groups and support services for both physical and mental health. Social prescribing is also an integral part of the improvements to AHCs for people with a learning disability and autistic people.

Another component of personalised care is personal health budgets. A personal health budget is an amount of money to support a person's health and wellbeing needs, which is planned and agreed between a patient (or their family/carer), and their local NHS team. It is not using new money, but using money already available for care and support and spending it differently to allow people to receive support that best suits them. It also enables people to make informed choices when their health changes.



An image from the NHS short film explaining the Comprehensive Model of Personalised Care.

Social Prescribing pilot in Luton

A new social prescribing pilot has been devised by Bedfordshire, Luton and Milton Keynes (BLMK) ICS, to explore how social prescribing, following an annual health check (AHC), might help to reduce health inequalities and improve health and wellbeing for someone with a learning disability.

Medics PCN, a network of five GP practices in Luton, is one of the PCNs involved in the pilot. When a person on the learning disability register attends a practice for their AHC they receive a leaflet describing the 'social prescription' activities and groups in and around Luton which are available for adults with a learning disability. The PCN is already seeing success with the scheme and to date over 30% of their patients with a learning disability have been referred to the social prescription service and have utilised a personal health budget (PHB) to improve their overall wellbeing.

For example, physical activities include disability football and martial arts; activities to improve mental health include friendship clubs, life skills activities are available around food and nutrition and money management, and independent life skills sessions include visits to libraries, museums, shops and the local area. Attendees also learn about relationships, communication, transport and personal hygiene.

Patients have used their PHB for activities including gym membership. James, an adult with a learning disability, used his PHB with agreement from the PCN to buy his winter walking boots and a coat so he could keep his wellbeing up through his daily activity of walking for health. Lucy, who is also an adult with a learning disability in the PCN described at her health check how she feels low during the winter months. Lucy's PHB was subsequently used to buy arts, crafts and jigsaws which she has been able to complete at home during the cold weather.

An image of Lucy who used her personal health budget to buy jigsaws and craft activities to prevent her from becoming low during the winter months.

Medics PCN aims to continue the pilot - their social prescriber and care coordinator plan to visit the residential homes for people with a learning disability in their area.

BLMK ICS also funded training in September 2022 for 13 Medics PCN staff, delivered by the MacIntyre Charity, to help them to support patients with a learning disability. The full day training included understanding the principles of person-centred planning, making reasonable adjustments to social prescribing and learning skills to support shared decision making with patients, families and carers.

Medics PCN will continue to offer all patients with a learning disability an appointment with a social prescriber and patients will be supported with an introduction to free activities and groups.

James, who used his PHB to buy new walking shoes and a waterproof coat so he could continue walking his dog and keep up his wellbeing during

STOMP and STAMP (Medication)

'STOMP' stands for stopping over-medication of people with a learning disability and autistic people with psychotropic medicines. These are medications which affect how the brain works. 'STAMP' supports the treatment and appropriate medication for children and young people.

The STOMP and STAMP programme helps children, young people and adults, with their family, doctor, pharmacist and other organisations involved in their care to consider removing medication, if they no longer feel it is beneficial. It also supports alternatives to medication where appropriate such as, NHS talking therapies, social prescribing and positive behavioural support.

In 2022/23 the STOMP and STAMP programme's work has included:

Prescribing:

The latest data[27] shows that psychotropic prescribing rates have fallen for people with a learning disability and autistic people, for medications including antipsychotics (often prescribed for behaviour thought to be challenging as well as for mental ill health), benzodiazepines (a type of sedative), and anti-epileptics (where prescribed other than to treat epilepsy). This is welcomed. However, the prescribing rates for anti-depressants have increased year on year for the last five years. Data show that people with a learning disability are still 16 times more likely to be prescribed anti-psychotic medication, and autistic people are seven times more likely to be prescribed anti-psychotics than the general population.

Training:

- We launched six new training modules with the educational platform MindEd - for self-advocates, health and social care staff and families/carers. The 30-minute modules explain the principles of STOMP, and how medicines are prescribed, reviewed, monitored and removed. The modules are available on the Health Education England website and by summer 2023 the six sessions had more than 7000 launches – a significant uplift since spring, reflecting the renewed prioritisation for STOMP and STAMP. The four top job roles accessing the online training were student nurses, nurses, doctors and pharmacists.
- We launched four new training modules in summer 2023 for specialist teams – i.e. psychiatrists, psychologists, pharmacists, specialist nurses, mental health trusts, community teams and staff in social care. These are being promoted extensively across health and social care networks.

Community of practice pilot:

- The Pharmacy Integration Programme funded a pilot led by the NHS England STOMP and STAMP team to look at the level of confidence among Primary Care Network (PCN) pharmacists (who sit within GP practices) to complete structured medication reviews (SMRs) for people with a learning disability and autistic people. Most regions in NHS England took part.
- The pilot included educational webinars and support from experts, and surveys to capture the progress of the 145 pharmacists who carried out

[27] Health and Care of People with Learning Disabilities Experimental Statistics 2021 to 2022 (December 2022), NHS Digital.

SMRs for people with a learning disability and autistic people. More than 100 people whose medication was reviewed are now on a dose reduction plan and 41 people have had their psychotropic medicine stopped.

Raising awareness of STOMP and STAMP:

◊ In January 2023 the STOMP and STAMP programme hosted an event for people with a learning disability and autistic people. This was led by Carl Shaw, a learning disability and autism advisor for NHS England. The session focused on helping people to communicate how they feel about their medication in an accessible format, for example, where they are non-verbal or might use Makaton, drama or art. The session also advised people on how to get involved in the decision making around their medication, as well as growing confidence to ask about medication and alternatives to medication.

◊ Delivering several STOMP webinars for pharmacists and pharmacy leaders in the newly formed ICBs, focusing on:

- how to improve communications with people with a learning disability
- workshops sharing the alternatives to medication
- sharing the learning and successes of the PCN pilot (above).
- ran 'deep dive' exercises (discussion groups) - for a range of health and care professionals working in specialist teams (learning disability in-patient and community based teams) social care professionals, people with a learning disability and autistic people and family carers to gain insights into the STOMP and STAMP programme in practice. This has highlighted the need for clearer standards of practice, professional accountability and improved inclusion of people and their carers in medication related decisions.

Figure 1 NHS England STOMP pledge commitments for healthcare providers

- We will actively explore alternatives to medication
- We will ensure people with a learning disability, autism or both, of any age and their circle of support are fully informed about their medication and are involved in decisions about their care
- We will ensure all staff within the organisation have an understanding of psychotropic medication including why it is being used and the likely side effects
- We will ensure all people are able to speak up if they have a concern that someone is receiving inappropriate medication
- We will maintain accurate records about a person's health, wellbeing and behaviour
- We will ensure that medication, if needed, is started, reviewed and monitored in line with the relevant NICE guidance
- We will work in partnership with people with a learning disability, autism or both, their families, care teams, healthcare professionals, commissioners and others to stop over-medication

NHS England pledge commitments for healthcare providers on stopping the over medication of people with a learning disability or autism.

London's STOMP in action

When safe and wellbeing reviews (SWR) of all people with a learning disability and autistic people who were being cared for in a mental health inpatient setting were completed in January 2022 the oversight review panel in South West London ICB included an Advanced Specialist Pharmacist (in Learning Disability). It was established that at least nine of the 35 reviewed patients had been prescribed psychotropic medicines without a clear documented mental health diagnosis – a key consideration for STOMP. As a result, changes to local quality monitoring were made to increase scrutiny in the use of psychotropic medicines.

South West London trialled specialist pharmacist input in CTRs/CETRs early on and over the last two years the pharmacist has advised on over 30 CTRs/CETRs for people within the South West London ICS footprint, reviewing - and where appropriate - reducing high doses of psychotropic medication and ensuring all the required monitoring is completed. The SWR panel recommended increased involvement of a specialist pharmacist in CTRs/CETRs, especially where people are prescribed complex medication regimes.

The Advanced Specialist Pharmacist has provided training to upskill more than 60 pharmacists in PCNs in South West London since July 2021 to do structured medication reviews with people. This has increased capacity and built confidence among the PCN pharmacists. The specialist pharmacist is also a member of the local LeDeR governance group and has promptly embedded any learning from LeDeR into the training. She now plans to deliver the same training to the pharmacy workforce in all acute trusts across South West London by Summer 2023 to compliment the Oliver McGowan mandatory training on learning disability and autism - with an added emphasis on medicines optimisation.

The wider NHS England London region also recruited a new project manager in early 2023 who will lead on STOMP and STAMP in the region – in the first role of its kind in the country. The role includes oversight of STOMP and STAMP, ensuring each ICS has proper governance in place to challenge inappropriate prescribing and facilitating the sharing of good practice and learning in the region.

New Initiatives

All About Health in the South East

A new accessible online resource to provide health information all in one place for people with a learning disability, their families, and people who support them is currently being co-produced. It will be hosted by Oxfordshire Family Support Network – a not for profit organisation.

The 'All About Health' initiative has received funding from Buckinghamshire, Oxfordshire and Berkshire West ICP and via the LeDeR programme. It is being developed through a partnership of advisory groups and people with lived experience of a learning disability, including members of the 'My Life My Choice' self-advocacy group. The project is chaired by the LeDeR Local Area Contact for Oxfordshire.

The resource will see existing information and resources on physical and mental health collated into one website. It will include guidance on: identifying and sharing good practice in all aspects of healthcare, films and real life stories already available, guidance on Health Action Plans, reasonable adjustments, and hospital passports, as well as information on specific conditions such as constipation, epilepsy and sepsis.

The website platform will be tested with support staff, families and people with a learning disability before it goes live in winter 2023 at which time it will be cascaded through the local authority, care provider organisations and shared via advocacy groups for people with a learning disability.

Oliver McGowan Mandatory Training on learning disability and autism

The Health and Care Act 2022 introduced a requirement for Care Quality Commission (CQC) registered service providers to ensure their employees receive learning disability and autism training appropriate to their role. Oliver McGowan Mandatory Training

is the Government's preferred training to meet this requirement. Health Education England (now part of NHS England) and health and care organisations are working in partnership to deliver the training in England. The e-learning includes learning relating to issues identified in LeDeR and beyond.

Tom Cahill, National Director for Learning Disability for NHS England, discusses why he champions the Oliver McGowan Mandatory Training on learning disability and autism for health and care staff in this short film.

Adapting NHS talking therapies - a pilot in Cambridgeshire and Peterborough

A mental health condition was one of the top three long-term health conditions among people with a learning disability who died in 2021[28]. A pilot launched as a result of the pandemic by the learning disability and autism team at Cambridgeshire and Peterborough ICS is working to reduce this - by improving access to talking therapies among people with a learning disability.

The team are working with staff with a learning disability background from Everyturn (formerly Insight) – a non-profit provider working on behalf of the NHS and local authorities - to develop a service for people with a learning disability.

There are already good one-to-one psychological services in the ICS for people with a moderate or severe learning disability and reasonable adjustments are in place in the mainstream NHS Talking Therapies service for autistic people. However, this pilot intends to make the mainstream talking therapies service more accessible and has used a behavioural model to adapt the therapeutic service for people who have a mild learning disability. Residents of Cambridgeshire and Peterborough with a learning disability can be referred to the service and in future may be able to self-refer.

[28] LeDeR Annual Report 2021, King's College London et al. (Page 21) https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf

While a typical talking therapies group is run over six weeks, the adapted sessions in the pilot, which include therapy and strategies to manage mental health, are delivered to six people with a learning disability over eight weeks. They are run in two-hourly group sessions in person, with breaks built in.

The first cohort in the scheme have already shown signs of improvements in their mental health, and the six members of the group also opted to stay in touch - creating their own social/peer support group. A short video explaining the initiative has been produced by the clinical lead and the clinician delivering the pilot.

The overall pilot will support a further five groups of six people throughout 2023. It will then be evaluated by measuring any improvements before and after the programme – asking the person concerned, any referrers, and family/friends to provide feedback where appropriate. Improvements against any clinical measures will also be reviewed. Depending on the outcomes the ICS, along with the regional and potentially national NHS Talking Therapies teams, will consider any next steps.

Applying ‘All Our Health’

The national LeDeR team advised the ‘All Our Health’ initiative – which hosts a collection of bite-sized learning on key public health issues online – with the development of new learning disability resources. The ‘Learning disability - applying All Our Health’ guide and a new e-learning module on learning disability were published in spring 2023. They are aimed at front-line health and care staff, ICSs, local authorities, and the wider public health workforce, to support people with a learning disability and their families. The resources, which were developed by the Office for Health Improvement and Disparities (OHID) in partnership with NHS England, also include recommendations of actions that managers and others in strategic roles can take to ensure good services and effective support where appropriate for anyone with a learning disability and their families.

Type 2 Diabetes – a new film

People with a learning disability have higher rates of type 2 diabetes then the general population.

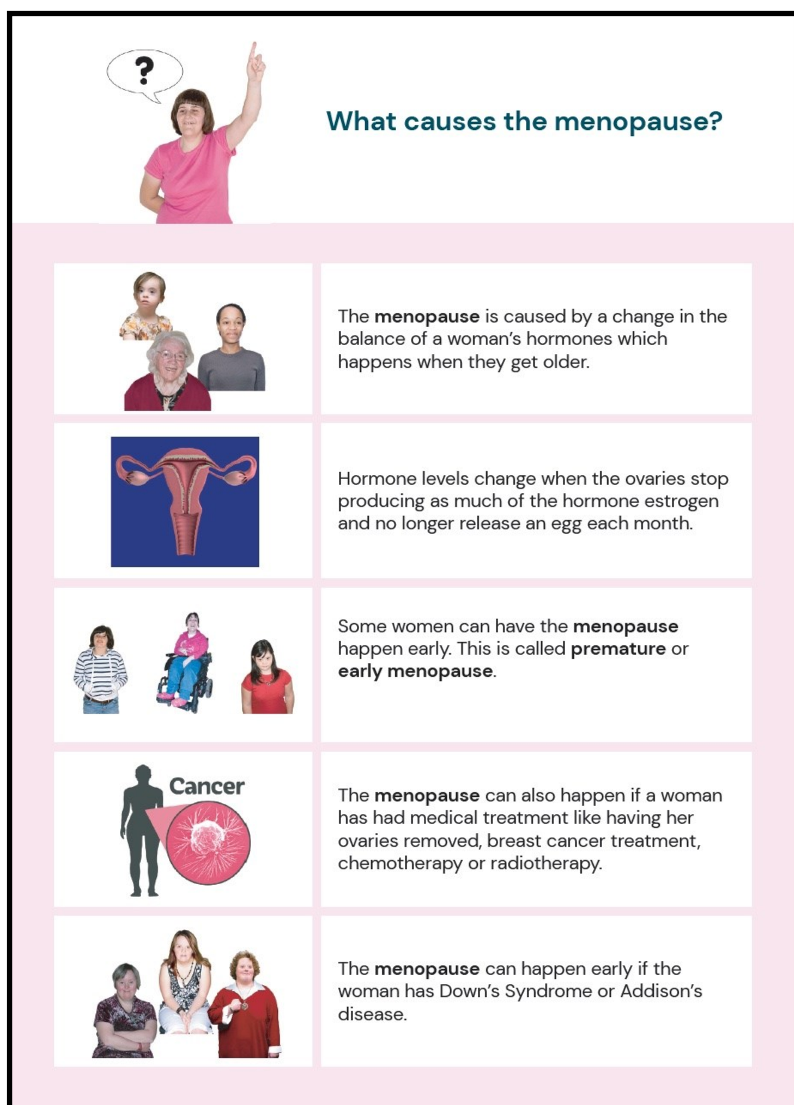
The North East and Cumbria Learning Disability Network and regional partners have developed a six week course with and for people with a learning disability and autistic people who have type 2 diabetes. The course includes reasonable adjustments and structured education. In this short film Natalie explains how the course has helped her to lose weight, eat healthier and understand more about her diabetes. NHS England shared the film at the start of Learning Disability Week in June 2023.

All about the perimenopause and menopause

A new easy read guide for women with a learning disability all about perimenopause and menopause has been published by *balance*, the menopause support website and app, in association with Dimensions, the not-for-profit organisation which supports people with a learning disability and autistic people. Some women can experience a number of symptoms from the hormonal changes during perimenopause – the time before a woman's periods stop – and after menopause, that is when a woman has not had a period for 12 months.

Menopause is often earlier in women with a learning disability and earlier still in women with Down's Syndrome[29].

Dr Louise Newson, the GP and menopause specialist who founded *balance* and the Newson Health Menopause and Wellbeing Centre, also interviewed Sharon Saunders, a woman with a learning disability, for her Dr Louise Newson podcast. The two women discussed some of the symptoms Sharon has experienced going through menopause including joint pains, headaches and hot flushes as well as the importance of asking for help. They also discuss how Sharon is starting hormone replacement therapy (HRT).



What causes the menopause?

The **menopause** is caused by a change in the balance of a woman's hormones which happens when they get older.

Hormone levels change when the ovaries stop producing as much of the hormone estrogen and no longer release an egg each month.

Some women can have the **menopause** happen early. This is called **premature** or **early menopause**.

The **menopause** can also happen if a woman has had medical treatment like having her ovaries removed, breast cancer treatment, chemotherapy or radiotherapy.

The **menopause** can happen early if the woman has Down's Syndrome or Addison's disease.

A page from the new easy read guide to perimenopause and menopause.

[29] Learning Disabilities and the Menopause (2003): https://pubmed.ncbi.nlm.nih.gov/12804309/

Using LeDeR data to inform local population health strategies

A new tool has been launched by LeDeR which enables NHS England and ICBs to access the latest data from LeDeR reviews to help inform their plans to improve the health of their local population. The LeDeR data tool was launched in April 2023 and includes data on demography*, health, and lifestyle among people with a learning disability and autistic people whose deaths were notified to LeDeR and where a review has been completed. All local leads in the LeDeR programme manage access to this insightful tool which can be used by anyone who needs the data to improve services in their local area.

The tool provides access to pertinent information within LeDeR reviews that may have affected the person, such as AHCs, mental capacity assessments, experience of the criminal justice system or DNACPR as well as information about avoidable causes of death, concerns about care, the grading of quality of care, and any positive practices.

The tool will be used to inform national, regional and local service improvement plans by enabling users to have a much more detailed understanding of their populations, causes of death, and the inequalities people face. With this greater understanding, any improvement projects can be targeted to the areas where they are likely to have the biggest impact in improving health outcomes and preventing premature mortality for people with a learning disability and autistic people.

*statistics could include geography, deaths, income, or the incidence of disease.

A screenshot from the LeDeR data tool which is available to NHS England and ICB staff working to improve the health of their local population.

Terms and acronyms used

ADASS – The Association of Directors of Adult Social Services

AHC – **annual health check.** This is offered to anyone aged over 14 who has a learning disability or is autistic and are important for maintaining health and wellbeing.

AHSN – **Academic Health Science Networks.** There are 15 AHSNs, set up by the NHS in 2013 to help the service with innovations to improve healthcare.

Autism – Autism diagnostic criteria includes: differences in social communication and interaction, highly focused interests or behaviours that appear to others as repetitive or restricted and, challenges with sensory hyper-or-hypo-sensitivity.

CCGs – **clinical commissioning groups.** These were clinically led statutory NHS bodies responsible for planning and commissioning healthcare services locally. They have now been replaced by ICSs under the Health and Care Act 2022.

CTR - care and treatment review. A meeting about an adult who has a learning disability or is autistic and who is either at-risk of being admitted to, or is currently detained in, an in-patient (psychiatric) service.

CETR - care, education and treatment review. A review that focuses on children and young people who either have been admitted or may be about to be admitted to a specialist mental health / learning disability hospital.

DHSC – **The Department of Health and Social Care.** The ministerial department that supports ministers in leading the nation's health and social care to help people live more independent, healthier lives for longer

DNACPR – do not attempt cardiopulmonary resuscitation. A DNACPR (or a 'DNR' or a 'DNAR') is an advance decision not to attempt cardiopulmonary resuscitation should a person experience cardiac or respiratory arrest.

Diagnostic overshadowing – where a person's symptoms of physical ill health are mistakenly attributed to either a mental health/ behavioural problem or as being inherent – i.e. exist because of - the person's learning disability.

EHCP – education and health care plan. An EHCP document sets out the education, healthcare and social care needs a child or young person needs beyond what a school can offer.

Health action plan - as part of a patient's annual health check (AHC), GP practices are required to produce a health action plan. This identifies the patient's health needs, what will happen about them (including what the patient needs to do), who will help and when this will be reviewed. The plan includes any key action points agreed during the AHC.

ICB – **integrated care board.** Every integrated care system (ICS) is led by an NHS integrated care board, an organisation with responsibility for NHS functions and budgets, and an integrated care partnership (ICP), a statutory committee bringing together all system partners to produce a health and care strategy. As ICBs are now legally established, CCGs have been abolished.

ICP – integrated care partnership. Statutory committees with representation from local government, the voluntary, community and enterprise sector (VCSE), NHS organisations and others who develop a health and care strategy for an area.

ICS – **integrated care system.** A group of health and care organisations which come together to improve the health of people in their area. There are 42 integrated care systems in England.

JCVI – joint committee on vaccination and immunisation. This committee advises UK health departments on immunisation and effective implementation of immunisation strategies to prevent infections and/or disease.

LACs – local area contacts. The LeDeR LAC role now sits within an ICB. LACs promote LeDeR learning at local level and across health and social care, they work with the LeDeR review team (who carry out LeDeR reviews into the death of a person with a learning disability or autism which was notified to the programme), and they also act at the contact person for the LeDeR regional coordinator.

Learning disability – 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 and coping independently.

LeDeR – **Learning from lives and deaths – People with a learning disability and autistic people** is a service improvement programme which aims to improve care, reduce health inequalities and prevent premature mortality of people with a learning disability and (from 2021) autistic people by reviewing information about the health and social care support people received. It is funded by NHS England.

LeDeR review – a LeDeR review looks at the health and social care that a person who died who had a learning disability or was autistic received that may have been relevant to their overall health outcomes. Reviews are not investigations or part of a complaints process.

NHS England – formerly NHS England and NHS Improvement – since April 2019 NHS England have worked as a single organisation to support the NHS and deliver improved care. On 1st July 2022 we became NHS England. In this report we have used NHS England to include activity carried out under the auspices of NHS England and NHS Improvement.

NHS Pathways - NHS Pathways is a clinical tool used for assessing, triaging and directing the public to urgent and emergency care services.

NHS Spine – this supports the information technology (IT) systems for health and social care in England, linking more than 23,000 systems in 20,500 organisations.

OHID – The Office for Health Improvement and Disparities – a government unit within the Dept. of Health and Social Care which promotes public health improvements across England. The role of Public Health England (PHE) moved to OHID in October 2021.

Restore2 and Restore2™ *mini* – Recognise early soft signs, take observations, respond, escalate; tools used to identify deterioration in health.

SEND – special educational needs and disability. A child or young person has special educational needs and disabilities if they have a learning difficulty and/or a disability that means they need special health and education support.

Social prescribing – this is when health professionals refer patients to support in the community, to improve their health and wellbeing.

SUDEP – the sudden, unexpected death of someone with epilepsy, who was otherwise healthy.

Task and finish group – a group of people who are responsible for delivering a specific objective within an agreed timeframe; they report back to a wider group with any recommendations, action plan or evaluation.

UKHSA - the UK Health Security Agency. This is a government agency in England and has been responsible for public health protection and infectious disease capability since April 2021 when it replaced Public Health England. It is an executive agency of the Department of Health and Social Care.

APPENDICES

Appendix 1: LeDeR Independent Advisory Group Members

Association of Directors of Adult Social Services (ADASS)	London School of Hygiene and Tropical Medicine (LSHTM)
Autistica	National Autistic Society
Care England	Mencap
Department of Health and Social Care (DHSC)	Office for Health Improvement and Disparities (OHID)
Dimensions	Pathways Associates
Down’s Syndrome Association	People First Merseyside
Health and Wellbeing Alliance	Race Equality Foundation
Inclusion North	Royal College of General Practitioners (RCGP)
Institute of Health Equity – University College London	Royal College of Psychiatrists
Learning Disability England	Stop People Dying Too Young
Learning Disability Professional Senate	Voluntary Organisations Disability Group (VODG)
Local Government Association (LGA)	

Appendix 2: Update on actions by NHS England

Theme	We said…	We Did…
Cancer	We will work with the cancer and cancer screening programmes to ensure that we understand the factors influencing avoidable deaths from cancer including prevention and treatment and determine actions to target awareness raising.	We commissioned our academic partners (KCL et al) to undertake two deep dives to help us to: 1. Understand why people with a learning disability and cancer are more likely to die from an avoidable death 2. Establish if reducing the age at which bowel cancer screening should be lower for people with a learning disability We commissioned a project in South East London which aims to identify and reduce barriers to cancer screening experienced by people with a learning disability. We presented cancer related LeDeR findings and best practice in the care of people with a learning disability and cancer to the Faster Diagnosis Cancer Network. We have collated a range of resources on cancer and screening which may be of use to heath and care professionals supporting people with a learning disability and autistic people in the new LeDeR Resource Bank. In 2023/24 Round 5 of the cancer improvement collaboratives will focus on people with additional conditions which include people with a learning disability and autistic people – at least 7 of the 11 collaboratives will consider how they can improve cancer services for people with a learning disability or autistic people and their carers.

Theme	We said…	We Did…
Constipation	We will deliver a social media campaign around constipation co-produced with people with lived experience and their families and carers and general practice staff.	We commissioned a new national constipation campaign which launched in July 2023 to raise awareness of the risks that constipation can pose to people with a learning disability. We have also added constipation resources to our new Resource Bank on the LeDeR website. We produced accessible materials and content for GP practices and websites used by social care staff. We supported a new app to help clinicians to check if the medication they are prescribing to someone with a learning disability could contribute to constipation. And our academic partner KCL also led a 'deep dive' about constipation. https://www.kcl.ac.uk/research/leder (See above report for more details of all of the above.)
Circulatory Conditions	We understand the prevalence of circulatory conditions as a cause of death and will work with the CVD programme to take appropriate actions to tackle hypertension and CVD in people with a learning disability.	We are working with the CVDPREVENT team to make data available on the quality of preventative CVD care that people with a learning disability receive on the CVD PREVENT website We commissioned our academic partners to undertake a deep dive to establish which circulatory diseases are causing the death of people with a learning disability so that we can target resources most effectively. It is anticipated that this will be completed by Summer 2024. The new LeDeR Resource Bank has a range of CVD resource available.

Theme	We said…	We Did…
CPAP	We will develop advice and support on sleep apnoea and continuous positive airway pressure machine usage (CPAP).	We worked with Baywater and Pathways Associates to deliver a project designed to support people with a learning disability and autistic people with sleep apnoea use their CPAP machines as prescribed. Over the last year Baywater and Pathways Associates have been working with people with a learning disability, autistic people, carers and health professionals to identify the barriers and enablers of using a CPAP machine. Using this information, the team have coproduced a range of resources (in different formats) for people with a learning disability, autistic people, health professionals and paid and unpaid carers. The information is designed to support people overcome the most reported barriers to prescribed use.
End of Life Care	We will work with the end of life care team, the Care Quality Commission (CQC) and others to further promote the use of appropriate documentation for DNACPR across all services over and above the SNOMED code for DNACPR documentation which is now in place.	We delivered training to CQC inspection teams and staff on end of life care for people with a learning disability and a general session about LeDeR. We commissioned our academic partners to undertake a deep dive to look at the appropriateness and effectiveness of CPR decisions in people with a learning disability. We have a range of resources to support with end of life care for people with a learning disability in the new LeDeR Resource Bank. In March 2023 we sent a letter to clinical leads and chief nurses in ICBs among many others (see more details in above report) to remind them and their systems of the importance of the appropriate use of DNACPR decisions for peo-

Theme	We said…	We Did…
Identifying deterioration in health	We will work with partners to support more carers / staff to be trained in the soft signs of deterioration.	We funded Cheshire and Wirral Partnership NHS Foundation Trust to deliver more face to face training on the 'decision support tool for physical health' (DST-PH) which helps staff proactively identify people with a learning disability at risk of premature mortality. We worked with Skills for Care, which supports the adult care sector, to make the RESTORE2™mini training more accessible for carers across England. This tool has been adapted for use in care homes to help carers detect the 'soft signs' of deterioration to facilitate earlier treatment. The training tool and slides are now available on the Skills for Care website. The NHS Long Term Workforce Plan has committed by 2028/29 to increase training places for learning disability nursing by 46% .

Theme	We said…	We Did…
Health and Care Passports	We will consider the findings of the 'hospital passport digital discovery' work to understand the best way to ensure that more people with a learning disability and autistic people have hospital passports which are taken account of when accessing health care.	Rather than a 'hospital passport' we have worked on a national template for a 'health and care passport' – in recognition that hospitals might play only a small part in people's health and care, with the information contained in 'hospital' passports is applicable to primary and community care too. We have established a Task and Finish group with representatives from ICBs, NHS Trusts and people with lived experience who are creating a template health and care passport with accompanying guidance for ICBs. The passport template will be based on the About Me standard, from the Professional Records Standards Body. About Me information includes the most important details that a person wants to share with professionals in health and social care, for example, how best to communicate with a person, or clarity on any health issues such as swallowing difficulties. The PRSB has created national standards for sharing the 'About Me' information between health and social care. These standards will enable systems to integrate health and care passports into local patient records while keeping ownership of the passport with the individual.

Theme	We said…	We Did…
Respiratory Health	We will roll out quality improvement initiatives for the respiratory projects which will be completed this year around pneumonia to support pathway change and improvement.	We commissioned BTS to deliver new guidelines on the management of pneumonia in people with a learning disability, which were published in March 2023 after extensive consultation. These are: • Guidance on aspiration pneumonia (AP) • Guidance on community acquired pneumonia (CAP) in people with a learning disability. We co-hosted a respiratory webinar for healthcare professionals in March 2023 to present the new BTS statements. The LeDeR and NHS RightCare teams have worked together to develop a new RightCare scenario focused on learning disability and aspiration pneumonia. This RightCare scenario was developed to support stakeholders in primary and secondary care to understand how the needs of people with a learning disability can be met. Two fictional stories are told which show the difference between a suboptimal and an optimal care pathway. The scenarios are designed to help all stakeholders in local care systems consider how they can ensure optimal care is delivered. We commissioned Sussex ICB to support the roll out of quality improvement initiatives using the new BTS guidelines and based on the RightCare scenario. The project used this work to support pathway change and improvement.. We commissioned our academic partners to undertake a deep dive to help understand more about the prevalence of aspiration pneumonia in people with a learning disability. We also commissioned a deep dive into the facilitators and barriers to uptake of vaccines for respiratory conditions in adults with a learning disability

Theme	We said…	We Did…
Working with our NHS colleagues and academic partners	We will work across the system to ensure that LeDeR reviews are high quality and can support local service improvement; that LeDeR data is accessible to local systems for them to interrogate to support local service improvement, improved commissioning and service provision; and that King's College London are commissioned to deliver deep dives into specific areas identified to support service improvement for people with a learning disability and autistic people.	We published a new LeDeR data tool in April 2023 which now enables NHS England and ICBs to access the latest data from LeDeR reviews. It will be used to inform national, regional and local service improvement planning by enabling users to have a much more detailed understanding of their populations, causes of death, and the inequalities people face. We commissioned a 'train the trainer' programme to support LeDeR reviewers and local systems to consider 'intersectionality' – that is how the different aspects of someone's identity such as race, culture and religion, can overlap – or 'intersect' – and significantly increase health inequalities in the quality of care and support provided to the person during their life. (See above report for more details). KCL have produced a deep dive comparing inpatient care and the use of restrictive practices for autistic children and young people, and those with a learning disability, in England, Scotland, Germany, Canada, and the US. The report is available at https://www.kcl.ac.uk/research/leder. KCL have also undertaken a deep dive into the onset and care of type 2 diabetes mellitus in people with a learning disability.

Appendix 3: Case studies by region 2022/23

Please note this is not an exhaustive list of regional initiatives and other work from the regions is mentioned throughout the report. The latest published ICB LeDeR annual reports can be found on ICB websites and provide a more comprehensive list of all of their local service improvement work locally.

EAST OF ENGLAND		
SUBJECT		**PAGE**
Cervical Screening	Tackling barriers to cervical screening in Herts	31
Frailty	Preventing and identifying frailty in Hertfordshire	22
Mental health	Adapting NHS talking therapies	66
Social Prescribing	Social Prescribing pilot in Luton	61
LONDON		
SUBJECT		**PAGE**
Annual Health Checks	An updated toolkit for London	42
Cancer	Transforming Cancer Services for London	29
COVID-19	Vaccine booster clinic in South London	14
Mental Capacity	Informed decisions on vaccination in London	52
STOMP and STAMP	London's STOMP in action	65
Urgent Care	Improving urgent care in London	58

Appendix 3: Case studies by region 2022/23

MIDLANDS		
SUBJECT		PAGE
Annual Health Checks	Children and young people in the Midlands	42
Cancer	Raising the risks of breast cancer in Worcester-shire	31
COVID-19	A thematic analysis of COVID deaths in the Mid-lands	15
Epilepsy	Improving Epilepsy Care in the Midlands	34
Epilepsy	Lincolnshire – epilepsy benchmarking programme in action	35
Health Inequalities	Removing barriers by working together	12
ICSs in Action	Making change happen in Birmingham and Soli-hull	36
Reasonable Adjustments	Improving reasonable adjustment services in Wol-verhampton	59

Appendix 3: Case studies by region 2022/23

NORTH EAST AND YORKSHIRE		
SUBJECT		**PAGE**
Annual Health Checks	In Brief - North East and Yorkshire	41
Cancer	Be Cancer Aware – a co-produced course in the North East	28
Diabetes	Type 2 Diabetes – a new film	67
Elective Care	Eliminating the elective care backlog for people with a learning disability	59
End of Life Care	End of life conversations in death cafés (INCLUSION NORTH)	50
End of Life Care	Training in end of life decisions (SPEAKUP)	51
Reasonable Adjustments	Making emergency departments accessible in Leeds	56
NORTH WEST		
SUBJECT		**PAGE**
Annual Health Checks	In Brief – The North West	41
COVID-19	Continuing COVID-19 safeguards	15
End of Life Care	Informing choices on DNACPR in the North West.	49
Reasonable Adjustments	Jack's Story	10
Reasonable Adjustments	Reasonable adjustment letters for GPs	54
Respiratory Health	Decision support tool for physical health – training	21

Appendix 3: Case studies by region 2022/23

SOUTH EAST		
SUBJECT		**PAGE**
Managing Health	All About Health in the South East	65
Respiratory Health	Identifying individuals at risk - a primary care pilot	22
SOUTH WEST		
SUBJECT		**PAGE**
Cancer	Tackling inequalities - a South West screening liaison service	30
Health Inequalities	Improving access to health in minority ethnic groups	47
Respiratory Health	Dysphagia awareness in the South West	18

Please note this is not an exhaustive list of regional initiatives and other work from the regions is mentioned throughout the report. The latest published ICB LeDeR annual reports can be found on ICB websites and provide a more comprehensive list of all of their local service improvement work locally.

Appendix 4: Integrated Care Systems

On 1 July 2022, integrated care systems (ICSs) became legally established through the Health and Care Act 2022. ICSs are partnerships of organisations that come together to plan and pay for health and care services to improve the lives of people who live and work in their area. Each integrated care system has two statutory elements:

- an integrated care partnership (ICP): a statutory committee jointly formed between the NHS integrated care board and all upper-tier local authorities that fall within the ICS area.

- and an integrated care board (ICB): a statutory NHS organisation responsible for developing a plan for meeting the health needs of the population, managing the NHS budget and arranging for the provision of health services in the ICS area.

Across England, local partnerships made up of all the public services that provide health and care – the NHS, GPs, local councils and the community and voluntary sector – plan how best to deliver these services so that they meet the needs of local people, are high quality and are affordable.

ICBs are also responsible for ensuring they address any learning from LeDeR reviews and improve the quality of services for people with a learning disability to reduce health inequalities and premature mortality. ICBs must have an executive lead on the Board who has a lead role for population groups including people with a learning disability and autistic people of all ages, and people of all ages with Down's syndrome. Guidance on their role from NHS England sets out that the executive leads should support the ICB in meeting the needs of people with a learning disability and autistic people.

A film by local experts by experience in Birmingham and Solihull (BSOL) shared their views on the strengths and weakness of the local system and hopes for the new ICS. This film was produced in September 2022 and is used in a range of forums including ICB meetings, LeDeR governance groups, and system summits.

For more information on ICSs see: NHS England » Integrated care