



Best practice and challenges in learning disability nursing 2020

**Putting the learning disability improvement
standards for NHS Trusts into practice**

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Foreword

In 2018, when I was the Executive Director of Nursing at NHS Improvement, I was very pleased to support the introduction of the Learning Disability Improvement Standards for NHS trusts. These standards are so important when delivering care to people with a learning disability and autistic people as they access NHS services. From respecting and protecting people's rights, to ensuring the voices of people and their families are heard, it is essential that services improve the care they deliver to some of our most vulnerable members of society.

Following my appointment to the position of Chief Nursing Officer for England, I remain absolutely committed to continue developing the standards and ensuring they are integral to delivering our aims to improve care for people with learning disabilities and autistic people as set out in the NHS Long Term Plan.



By taking a longer-term England-wide approach, I am confident we can help to reduce the unwarranted variations in care and outcomes which many people with learning disabilities experience. By setting out the necessary benchmarks, and supporting trusts to assess their services, we enable them to understand their strengths and weaknesses, and how improvement can best be delivered.

This work is providing us with valuable evidence to work in partnership with others to develop improvement tools and to shape the ongoing development of national policy.

The Changing Our Lives team has gathered some truly inspirational stories from NHS trusts across England, showing how action is being taken to ensure that people with a learning disability and autistic people receive the care and support that they are entitled to. I am especially heartened to see so many learning disability nurses at the centre of these initiatives. This amplifies the unique role they have at the forefront of driving improvement for the individuals and families they serve.

Ruth May

Chief Nursing Officer for England

Changing Our Lives



Changing Our Lives is a rights-based organisation that works alongside disabled people and people with lived experience of mental health difficulties, as equal partners to find solutions to social injustice and health inequality.

People with learning disabilities and autistic people face significant health inequalities in the UK today. They still die younger than their peers. They are still more likely to receive poor quality health care, and are less likely to be able to access mainstream health services. Far too many people are still in inpatient settings because their needs have not been met in their communities.

Changing Our Lives is committed to raising awareness of health inequalities and sharing best practice so that the standard of healthcare can be raised for all people with learning disabilities and autistic people everywhere. We are proud to work with NHS England and NHS Improvement on this document which captures some of the best practice happening in line with the Learning Disability Improvement Standards.

Introduction and background to the work

In 2018, NHS Improvement (NHSI) published the learning disability improvement standards for NHS trusts. These four standards, if met, identify NHS Trusts as delivering high quality services for people with a learning disability and/or autistic people, and their families.

In 2019, disabled people, families, and health care professionals said that they wanted NHSI to identify and distribute some best practice examples that would help all NHS Trusts to make the standards a reality for everyone.

Changing Our Lives connected with learning disability nurses and other clinicians in clinical settings across England, who spoke honestly about what excellent care for people with a learning disability and/or autistic people looks like. They offered inspirational stories of innovative teamwork between professionals, individuals, and families that meant people got access to healthcare in ways that had never previously been considered possible.

However, it also became apparent during these conversations that there were still significant barriers and challenges to ensuring excellent care for everyone, all of the time. As a result, this document addresses some of those challenges and aims to contribute to a national conversation about how the role of the learning disability nurse can be developed and complemented, to maximise its impact.

This document comprises 79 examples of best practice taken from across 16 NHS Trusts, a regional learning disability network and three voluntary sector organisations.



**The challenges faced by
learning disability nurses
fall into the following areas**

Be careful of the learning disability label...

The diagnoses of 'learning disability' or 'autism' tell you very little about an individual person, especially in the clinical context. Practitioners need to respond to the individual and their needs, rather than have their judgement clouded by preconceived ideas about people with a learning disability and/or autistic people. As there is a wide range of very different people who are labelled as having a learning disability, the amount of variation in both their needs and urgency are significant. Where the label can be helpful, is in alerting healthcare practitioners that they may need to use different ways of communicating, and that a person may have more difficulty understanding or retaining information than other patients may.

Understanding that reasonable adjustments must be individualised

Often reasonable adjustments are spoken of as if they can be lifted off the shelf and yet in practice they are bespoke to the individual. What is accessible for one person may be meaningless to another. The most significant reasonable adjustment that any practitioner can offer a person with a learning disability and/or an autistic person, is to make time to listen and find out what works for them.

Communication between teams and disciplines

Even among learning disability specialists, there can be a lack of understanding and communication in terms of people's needs, continuity of care from one team to the next and a shared understanding of how people present differently than usual, in different circumstances. For example, a community learning disability nurse who supports a

person to enjoy a healthy lifestyle, may see a very different picture to a nurse in an acute hospital, who only meets and provides care to a person when they are very unwell or in pain. Families, carers and other professionals in the person's life will all have their own unique understanding of that person too.

Watering down the learning disability acute liaison nurse role

Some acute hospitals have no learning disability liaison nurses; whilst others may have a liaison nurse who operates in a more senior, strategic position and has limited direct interaction with patients. In some trusts, there may be a single liaison nurse who has wide ranging responsibilities for ensuring adherence to the Mental Capacity Act, including authorising deprivations of liberty; supporting people with mental health needs, as well as those with a learning disability; and also, leading on the trust's safeguarding strategy. Sometimes nurses work across children's and adults' services in a single trust. Roles can become unwieldy or diluted, reducing the ability of liaison nurses to improve people's experiences and outcomes. Acute liaison nurses told us that they value links in with other learning disability specialists, who can both challenge and support professional development.

Autism can be an afterthought...

Nurses respond to individual people's needs, whether they have a learning disability and autism, or are autistic with no learning disability. However, autistic individuals who have no learning disability can be left out of service specifications, and may thereby experience health inequalities. The needs of autistic people should be taken into account during service development, delivery and evaluation.

Not another pathway...

Although pathways, hospital passports and other initiatives have their place, there is no use putting them in place if they aren't utilised properly. Pathways that are created need to reflect and be part of day-to-day practice for practitioners. Tools like hospital passports need to routinely and consistently be recognised and used in order for people, families and practitioners to place their trust in them. In short pathways don't ensure good practice on their own, and used poorly they can do more harm than good.

Flagging

Electronic flagging in patient record systems can be clunky, especially where trusts use more than one different system. Information about a person, such as what reasonable adjustments they need, should be clear across all systems. Having to exit one piece of software or database, to go and check another, makes it easy to miss information or to forget to check. If the system isn't intuitive, busy practitioners won't use it.

Using the skills of the learning disability nurse strategically

Diagnostic overshadowing, seeing the label and not the person; and lack of awareness or training, can mean that some universal health services shift all the responsibility for supporting people with a learning disability and/or autistic people, to learning disability nurses. This can mean that people don't benefit from the expertise and experience of other clinical professionals, or are unable to access certain resources. The unique skills and experiences of learning disability nurses should be used to enrich other areas of practice and make mainstream services work for everyone.

The creativity of learning disability nurses being used to overcome shortfalls elsewhere

Some of the most creative examples that learning disability nurses told us about, concerned people who had previously experienced entrenched and recurrent difficulties accessing health care; and where a crisis had developed, where even providing basic health support posed a real challenge. Although the examples given showed great teamwork and ingenuity, these situations could often have been avoided if support with health had worked better, throughout the person's life. This would free up the creative talents of learning disability nurses to support people to enjoy healthy lifestyles, rather than just responding to downfalls across wider support systems.

Relationship builders

Learning disability nurses can act as unofficial health advocates for people with a learning disability and/or autistic people, where they align themselves with the needs of the person, rather than services. We have heard many examples of learning disability nurses pulling together people and resources, to creatively meet the needs of the person. This part of their work must be valued and supported.

If the nurse goes, the practice goes...

Where learning disability nurses work alone or in very small teams, especially in liaison roles in universal services, good practice often relies on individual staff, rather than being systemically embedded across trusts. Many learning disability nurses we spoke to, weren't managed by another learning disability nurse, and expressed a need to build a community of practitioners to discuss, debrief and problem-solve together.

Good practice

To uphold confidentiality, all names in this section have been changed apart from where specified.

The learning disability improvement standards for NHS Trusts

The learning disability improvement standards re-emphasise the expectations from a range of existing national policies and legislation. Each standard is supported by a range of improvement measures. These are the things trusts are expected to do, to ensure they meet the standards. Through routine and repeated benchmarking of performance against peers, all trusts, whether they provide universal or specialist healthcare services, can understand their areas of relative strength and weakness and can see the scale of improvement that is possible.

The standards are broken down into 4 areas:

1. Respecting and protecting rights
2. Inclusion and engagement
3. Workforce
4. Specialist learning disability services

The first three standards should be met by all trusts; the fourth is specifically for trusts that provide services commissioned exclusively for people with a learning disability, autistic people or both.

Trusts are expected to work with local stakeholders to develop and implement improvement action plans. They are also expected to publish their performance against the standards in their annual quality accounts, to demonstrate to the population they serve, how they measure quality of services and whether quality is improving.

The following section provides examples of positive practice, where these measures have been met. Each standard has its own improvement measures. The following section provides examples of best practice where these measures have been met.

Standard 1: Respecting and protecting rights

Improvement measures:

1. Trusts must demonstrate they have made reasonable adjustments to care pathways to ensure people with a learning disability, autism or both can access highly personalised care and achieve equality of outcomes.
2. Trusts must have mechanisms to identify and flag patients with a learning disability, autism or both from the point of admission through to discharge; and where appropriate, share this information as people move through departments and between services.
3. Trusts must have processes to investigate the death of a person with a learning disability, autism or both while using their services, and to learn lessons from the findings of these investigations.
4. Trusts must demonstrate that they vigilantly monitor any restrictions or deprivations of liberty associated with the delivery of care and treatment to people with a learning disability, autism or both.
5. Trusts must have measures to promote anti-discriminatory practice in relation to people with a learning disability, autism or both.

Standard 1: Respecting and protecting rights

Improvement measure: Trusts must demonstrate they have made reasonable adjustments to care pathways to ensure people with a learning disability, autism or both can access highly personalised care and achieve equality of outcomes.

Quick, collaborative action

Staff at Errol's residential home became concerned about him when he began hitting his eyes and showing a change in his behaviour towards others. Errol is autistic and has severe learning disabilities. An optician was unable to examine Errol's eyes. His community learning disability nurse contacted the Learning Disability Lead at Imperial College Healthcare NHS Trust for help with an urgent appointment. Working with the matron at Western Eye Hospital, the Learning Disability Lead arranged for a quiet environment for Errol and his family and supporters to wait, and an immediate appointment with a specialist paediatric consultant instead of the usual A&E doctors. The consultant diagnosed detached retina in both eyes, and quick action was needed to reduce the risk of vision loss. The ophthalmic surgeon attended straight away to talk to Errol and his family about his treatment options, and a nurse carried out Errol's pre-assessment checks so he did not have to come back to hospital before his surgery. Errol successfully had his surgery the following week.

– Imperial College Healthcare NHS Trust

"Making reasonable adjustments means people don't have to fit into services; services are shaped to fit around people's needs."

Getting the basics right

North Middlesex University Hospital Trust recently worked with Mencap, as part of their 'Treat Me Well' campaign to get funding for a Changing Places Toilet. This simple reasonable adjustment makes visiting hospital or being an in-patient much easier and more comfortable for anyone who cannot use a standard disabled toilet, but is sadly not seen on every hospital premises.

– North Middlesex University Hospital Trust

Getting the message across

London North West University Healthcare NHS Trust use a range of tools such as communication books, pictures and sign language so that patients can communicate in a way that works for them. Patients with a learning disability are given picture menu books with real photos of the food on offer and easy read descriptions so that they get a real choice about what they want to eat, rather than a meal chosen by staff.

– London North West University Healthcare NHS Trust

At Barts Health NHS Trust, social stories are written that include real photographs of the hospital to allow patients to prepare for their visit. When Graham had a triple heart bypass, his family sent photos of his home and bed to the Lead Nurse for Learning Disabilities so they could be included in his story about going home from hospital.

– Barts Health NHS Trust

Standard 1: Respecting and protecting rights

Improvement measure: Trusts must demonstrate they have made reasonable adjustments to care pathways to ensure people with a learning disability, autism or both can access highly personalised care and achieve equality of outcomes.

Being creative and personal

Becky is in her 20s and is a big Gary Barlow fan. She attends a Health Expert Group at Waddiloves, a specialist learning disability health centre in Bradford. Recently Becky was prescribed glasses but it took her a while to adjust to wearing them and she often didn't want to wear them or forgot to put them on. When staff at Waddiloves heard about Becky's musical tastes they did some research and found that Gary Barlow is a glasses wearer. Staff printed some pictures for Becky of Gary in his glasses, and Becky now wears her glasses with pride. Staff say that good reasonable adjustments are all about being creative and personal.

– Bradford District Care NHS Foundation Trust

Changing your approach

Meg came into the Emergency Department at Kings Mill Hospital and was very frightened. She was scared about the equipment and the staff uniforms. Staff took Meg to a different room. The learning disability nurse specialist took off her uniform and put on ordinary clothes. The doctor took away some of the equipment.

Meg couldn't let the nurse do the health checks using the hospital equipment. So the health staff let her use a FitBit to do these checks.

Meg was scared about having an X-ray. The health staff arranged for her to stand up instead of lying down. They let her support worker go into the X-ray room with her and hold her hand.

– Sherwood Forest Hospitals NHS Foundation Trust

Being a familiar face

At the beginning of the COVID-19 pandemic Jamie's health started to decline and he needed to be admitted to hospital. Jamie was anxious as he was originally offered to be admitted at a time when he had no support. The safeguarding lead at the hospital he was admitted to knew Jamie from a previous role and liaised with him and with his community learning disability nurse to plan his admission, to meet him when he arrived at the hospital and to ensure that the Accident and Emergency ward knew what reasonable adjustments Jamie would need.

Jamie was not in touch with his family, so while he was in hospital, his multidisciplinary team took turns to visit or call Jamie including the weekends, which helped with his distress at being in hospital.

Jamie was nervous about having a cannula put in and about having the scans he needed. When he is not unwell, Jamie helps to deliver patient-centred training. His community learning disability nurse suggested to Jamie that he could make videos about his experience in hospital to share with the rest of the training team as a learning exercise. When it was reframed like this, Jamie was happy to go ahead with procedures that he had previously found very difficult.

– Barnet, Enfield and Haringey Mental Health NHS Trust

Standard 1: Respecting and protecting rights

Improvement measure: Trusts must demonstrate they have made reasonable adjustments to care pathways to ensure people with a learning disability, autism or both can access highly personalised care and achieve equality of outcomes.

Going beyond the extra mile

Ben needed dental treatment during the COVID-19 pandemic. He lives in Rampton High Secure Hospital and has a core staff team that he feels particularly comfortable and secure with. Because of the aspiration risk inherent in dentistry, everyone in the room with Ben needed to wear specific face masks, which can't be fitted correctly over a beard. The members of staff that Ben feels most comfortable with all had beards. They shaved them off so that they could go with Ben and ensure he had the treatment he needed safely.

– Nottinghamshire Healthcare NHS Foundation Trust

Time and patience

When Aliyah's psychiatrist requested that she have an Electrocardiogram Test (ECG), Aliyah could not bring herself to even look at the ECG machine. Aliyah was in her 50s and had Down Syndrome. The only intervention she had agreed to was to have her blood pressure taken. Aliyah had familiarisation sessions at home and at Waddiloves, a specialist learning disability health centre in Bradford. After 14 weeks of support to reduce her anxiety Aliyah was able to have the ECG test which showed she had bradycardia. Aliyah will need another ECG, but she is no longer frightened of having the test done.

– Bradford District Care NHS Foundation Trust



Standard 1: Respecting and protecting rights

Improvement measure: Trusts must have mechanisms to identify and flag patients with a learning disability, autism or both from the point of admission through to discharge; and where appropriate, share this information as people move through departments and between services.

The importance of flagging

When a patient with a learning disability or who is autistic arrives at University Hospitals Birmingham this is flagged to the Lead Nurse for Vulnerabilities at the Trust. The Trust saw their flagging increase by 100% over 2018/19. The Trust has introduced their own hospital passport that links into relevant learning disability improvement standards and prompts staff to ask if the person has had an annual health check. This is filled in by someone who knows the person well, but is shared widely across healthcare teams in Birmingham.

– University Hospitals Birmingham NHS Foundation Trust

Truly co-ordinated care

Co-ordinate My Care was an End of Life pathway, but in 2018 the Learning Disabilities Lead Nurse at London North West University Healthcare NHS Trust ran a pilot to see if it could be used to improve the quality of life for patients with a learning disability. Some of the people involved in the original cohort have managed to stay out of hospital for over a year and now the pathway has been rolled out more widely. It consists of an electronic record that is shared widely across the many points at which a person may come into contact with health services such as the Acute Trust, Primary Care Trusts, NHS111, London Ambulance Service and the A&E Department. Any clinician in one of the many services can complete the care plan with a person and their family. This includes specific information about what ongoing care the person is receiving, what works for them in an emergency and what medication they are on. This information is available instantly to all the relevant teams and is critical to making quick and effective decisions in an emergency. This has been particularly helpful during the COVID-19 pandemic to reduce confusion among different teams.

– London North West University Healthcare NHS Trust

Standard 1: Respecting and protecting rights

Improvement measure: Trusts must have mechanisms to identify and flag patients with a learning disability, autism or both from the point of admission through to discharge; and where appropriate, share this information as people move through departments and between services.

Sharing Margaret's legacy

Margaret had lived most of her life without a diagnosis of 'learning disability'. By the time she was referred to her local Community Learning Disability Team she had been through extensive testing and treatment for breast cancer with no family or support network around her, and had just discovered that her cancer had spread again. Margaret's Palliative Care Consultant had worked with people who have a learning disability and recognised that Margaret would benefit from being linked in to her local Community Learning Disability Team. The difference this made to the end of Margaret's life was immeasurable, and in 2020 Margaret died with dignity, surrounded by people from the support networks she had established.

Before her death Margaret told her story, and this has been made into a training package that is being used to train trainers in a range of teams, including community services, acute trusts, palliative care and hospice teams, social care providers, day services, GPs, commissioning teams and the voluntary sector. The aim is to get the message out as widely as possible so that people in all professions think "What would I do next time I meet a Margaret?"

We have used Margaret's real name in this story, as she was very proud of the contribution she made.

You can see her story here: <https://www.northerncanceralliance.nhs.uk/pathway/early-diagnosis/learning-disability/palliative-care-and-end-of-life/>

– North East and Cumbria Learning Disability Network

A dedicated pathway for people with complex health needs

Patients attending the emergency department at Kings Mill Hospital, who are on home ventilation, trigger a Recurrent Admission Patient Alert (RAPA), which alerts the respiratory service to their attendance, allowing them to liaise with Emergency Department (ED) regarding their care. The service has developed a pathway, allowing direct access to the respiratory ward, under their named clinician, regardless of whether the primary complaint is a respiratory one. Family or carers are given a letter, which they present in ED outlining this. Many people with a learning disability who have very complex health needs attend hospital often and are on this pathway. It means that instead of going to various different wards for different specialisms they always come to the respiratory ward, where staff have a high level of clinical skill and experience of their specific health needs, and where the person and their family are cared for by a familiar staff team who know them well.

– Sherwood Forest Hospitals NHS Trust.

Standard 1: Respecting and protecting rights

Improvement measure: Trusts must have processes to investigate the death of a person with a learning disability, autism or both while using their services, and to learn lessons from the findings of these investigations.

Learning from known risks

The Purple Pathway at Imperial College Healthcare NHS Trust prompts staff with key information that they need to consider at admission and discharge for each patient with a learning disability or who is autistic. This flags up key risks highlighted by the Learning Disabilities Mortality Review (LeDeR) such as pneumonia, constipation or seizures.

– Imperial College Healthcare NHS Trust

Taking a multi-faceted approach to risk

MacIntyre and Dementia UK have recently hired the UK's first Learning Disabilities Admiral Nurse. MacIntyre deliver webinars for their learning disability support staff on key risk factors raised through the LeDeR report, such as dysphasia. The Learning Disabilities Admiral Nurse is involved in this training to explain how dementia interacts with each of these risk factors and how that may change the care and support a person with a learning disability and dementia needs.

– MacIntyre and Dementia UK

The North East and Cumbria Learning Disability Network and the Access to Acute (A2A) Network have developed an E-Learning training package aimed at all staff who work in an acute trust. The training includes key findings from the LeDeR Programme. This also includes real life case studies that were outlined in the original Death by Indifference report.

– North East and Cumbria Learning Disability Network

Processes for learning from deaths

At Kings Mill Hospital the Learning Disability Specialist Nurse checks all deaths of people with learning disabilities in the hospital to assess if anything could have been done differently. The deaths are reported to the Trust Board every three months as well as to the LeDeR team. The Learning Disability Specialist Nurse and the Safeguarding Lead discuss the review findings and this information is taken to a Mortality Surveillance Group, a multidisciplinary health and social care group.

– Sherwood Forest Hospitals NHS Trust

University Hospitals Birmingham NHS Foundation Trust hold a steering group for vulnerable people and manage an action plan based on findings from patient deaths. The group collects and monitors evidence of embedded changes. The experiences of family carers for people with a learning disability are included in training.

– University Hospitals Birmingham NHS Foundation Trust

Responding to emerging risks

At North Middlesex University Hospital NHS Trust the Learning Disability Service has been doing rapid reviews of deaths for people with learning disabilities throughout the COVID-19 pandemic. Although this has been challenging the information is key to responding quickly to the changing situation and preventing early deaths for people with a learning disability.

– North Middlesex University Hospital NHS Trust

Standard 1: Respecting and protecting rights

Improvement measure: Trusts must demonstrate that they vigilantly monitor any restrictions or deprivations of liberty associated with the delivery of care and treatment to people with a learning disability, autism or both.

Raising a voice for patients

In Nottinghamshire, the Acute Liaison Nurse has been raising awareness among mainstream teams about the importance of the Mental Capacity Act and reducing restrictive practice.

When Craig was referred for day surgery by his consultant, the day surgery team spotted that the Mental Capacity Act hadn't been applied, there was no consent form completed with Craig and no reasonable adjustments had been put in place.

The team immediately got in touch with the Acute Liaison Nurse who convened a virtual Best Interests meeting with Craig's family, his support team and his occupational therapist and they were able to put a plan in place for Craig to have the surgery in the least restrictive way for him.

For Craig, this meant having the first appointment of the day. Craig enjoys art classes so a side room was set up to look like an art classroom and he took some of his artwork with him to do while he waited. All information was given to Craig in an accessible format and he brought his preferred keyworker along with him on the day of surgery.

– Nottinghamshire Healthcare NHS Foundation Trust

VALIDATE

VALIDATE stands for Vulnerable Adults with Learning Disability Anaesthesia Team. It is a new service set up by the learning disability nurse and two anaesthetists at Brighton and Sussex University Hospitals NHS Trust. The team helps with the best interest process and coordinating the care of patients with a learning disability. They aim to minimise admissions, prevent on-day cancellations of

surgery and support people and families. When a person with a learning disability is referred to surgery, a member of the Learning Disability Liaison Team attends the initial outpatient department meeting to establish the patient's best interests. They then communicate with the person and their family or carers, advise on the best location for the person to be seen, coordinate with any other departments involved for other tests and procedures and organise a theatre session and anaesthetist for the person.

– Brighton And Sussex University Hospitals NHS Trust and Sussex Partnership NHS Trust

Training for everyone

At Kings Mill Hospital staff are trained annually on the Mental Capacity Act. The Learning Disability Specialist Nurse provides training on the Deprivation of Liberty Safeguards to all staff.

– Sherwood Forest Hospitals NHS Trust

Led by the North East and Cumbria Learning Disability Network and the Access to Acute (A2A) Network a set of Learning Disability Diamond Acute Care Pathways and E-Learning have been developed for all Acute Trusts in the North East and Cumbria. Within these it covers the importance and practical application of the Mental Capacity Act. Specific prompts about the Mental Capacity Act are included in their planned admission, emergency admission and discharge pathways.

– North East and Cumbria Learning Disability Network

Standard 1: Respecting and protecting rights

Improvement measure: Trusts must have measures to promote anti-discriminatory practice in relation to people with a learning disability, autism or both.

Challenging assumptions

When COVID-19 first hit there was national concern about the misuse of Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) notices for disabled people. The lead learning disability nurse at Northwest University Healthcare NHS Trust acted fast and audited all the DNACPRs for people with a learning disability under her care. She asks, "Has it been discussed with the person? Do they have capacity? If not, was an IMCA involved? What is the reason? If someone has made a mistake and learning disability is included as a reason I tell them to get rid of that and put a proper reason. Having a learning disability is no more reason to have a DNACPR than being Chinese or having blonde hair." She says that her uncompromising standards have led to more understanding of this issue in the wider team.

– London North West University
Healthcare NHS Trust

Making it real

Martin is an active self-advocate who does a lot of his campaigning work in Birmingham. When the Lead Nurse for Vulnerabilities in Birmingham wanted to bring the question "What does good look like?" to life for nursing staff in the Trust she asked Martin to help her make a series of posters showing what good looks like for him if he ever needs hospital treatment. This personalises the message and makes it about the individual not the label. It gives staff a tangible benchmark to work towards in every interaction they have with people with a learning disability.

– Birmingham University NHS
Foundation Trust

Project Search

11 young people with a learning disability took part in Project Search for one academic year in 2019/20. They completed work placements across the Trust in Human Resources, Pharmacy, Oncology, Outpatients, Library, eRostering and Diagnostic Imaging, had daily sessions with a job instructor, and had staff mentors in the workplace. The roles were challenging, varied and supportive and by the end of the placement most of the students were actively applying for vacancies within the Trust and beyond. Department managers said that having the students on placement made a positive impact within their departments. As well as the impact of their work, having the students around for a year allowed other staff to get to know a few people with a learning disability really well, and demonstrated the specificity of people's needs and communication styles.

– North Middlesex University Hospital
Trust

Assessing by need, not by label

At Barts Healthcare NHS Trust a Standard Operating Procedure in A&E has been developed over 5 years. When a person with a learning disability is admitted, it prompts staff to consider what the person is having difficulty with and how long they are able to wait to be seen so that cases can be prioritised based on individual clinical need, rather than on the label of learning disability. Not everyone will need to be seen urgently every time. However, everyone with a learning disability is reviewed by a senior clinician, who will be highly experienced. This reduces the risk of diagnostic overshadowing interfering with an accurate diagnosis.

– Barts Health NHS Trust

Standard 1: Respecting and protecting rights

Improvement measure: Trusts must have measures to promote anti-discriminatory practice in relation to people with a learning disability, autism or both.

Working together to make healthcare possible

Simon is autistic and was showing increasing signs of distress, including hurting himself and his family. Some tests were needed to find out if Simon's physical health was causing his change in behaviour.

Simon couldn't bear even the briefest touch so any observations, tests or investigations were impossible while he was awake. The Lead Nurse for Learning Disabilities worked with Simon's mum to create a plan to safely get him into hospital.

Simon was brought to hospital in his own car and given oral sedation while he was still in his own car in the car park. When Simon was very sleepy he was driven to the ambulance bay outside A&E. Rather than wake Simon by moving him into a stretcher, the anaesthetist got into Simon's car to place a cannula and give stronger sedatives, so that it was possible to move him into A&E.

Simon had a full body examination, blood tests, CT scan and ophthalmology check to rule out a physical health cause. Simon's mum was with him the whole time so she could see that he was well cared for.

Simon's visit was an innovative example of joint working between the A&E, ITU, General Medical, Ophthalmology, Radiology and nursing teams. However, it also highlighted the fact that up until this point, Simon had not had even the most basic of healthcare.

– Barts Health NHS Trust.

Bridging gaps in the system

Daphne has a learning disability and was assessed for dementia by a GP during the national lockdown. Daphne was asked "Can you name somewhere you've been in the last few weeks?" Understandably, Daphne struggled with this question as, like many others in the UK, she hadn't been anywhere in the last few weeks.

Many GPs use a generic tool to assess for dementia, which isn't relevant to people with a learning disability. Questions such as "Who is the current monarch?" can be difficult to understand.

The Learning Disabilities Admiral Nurse at MacIntyre supports many NHS learning disability nurses who are able to take time and use their unique skills to ensure that people with a learning disability and dementia are diagnosed and treated promptly. Early support can have a massive impact on outcomes for a person with dementia and without a diagnosis a person isn't eligible for memory clinics and other resources.

Some learning disability teams are now setting up their own memory clinics, which means that people get the support they need, but still shows how far mainstream dementia services have to go to be accessible for people with a learning disability.

– MacIntyre and Dementia UK

Standard 1: Respecting and protecting rights

Improvement measure: Trusts must have measures to promote anti-discriminatory practice in relation to people with a learning disability, autism or both.

Equal access to primary health care

The Primary Care Self-Assessment Framework challenges all GP Practices in Sunderland to achieve Bronze, Silver or Gold status for the quality of their care and treatment of people with a learning disability. The three levels build upon each other and start with basic measures such as providing Easy Read letters and logging people's reasonable adjustments.

At the Silver level, practices should make sure that all patients with a learning disability are accessing basic health screening.

Fiona's GP practice noticed that Fiona had declined her last few invitations for a smear test, and referred her to the Health Promotion Team who knew Fiona well. The Health Promotion Team showed Fiona some Easy Read information and allowed her to look at a speculum so she would know what to expect. They taught her some breathing exercises and supported her to make an appointment for her smear. The GP queried whether Fiona needed a smear, and the nursing team was clear that she had a right to a smear just like any other woman. The GP gave Fiona some diazepam to help with anxiety on the day and a nurse was chosen who knew Fiona well. The nurse reassured Fiona throughout and her results came back normal. Fiona is very proud that she overcame her anxiety and took this step for her health.

– Cumbria, Northumberland, Tyne and Wear NHS Foundation

Ensuring equality in cancer services

People with a learning disability are less likely to be screened for cancer than non-disabled people, are more likely to be diagnosed at a late stage, and are more likely to receive lower quality cancer care and end of life care than non-disabled people. The North East and Cumbria Learning Disability Network and Macmillan Cancer Support established a 4-year program that implemented a wide range of measures to tackle the inequalities in cancer treatment for people with a learning disability.

Their innovative approach has led to a range of Easy Read materials, peer education projects, staff training materials and improvements to screening, flagging and treating patients with a learning disability.

Now that the initial 4 years have passed, the project will continue to be funded and delivered by the North East and Cumbria Learning Network. They have developed a website to share much of their learning helping others adapt and adopt their work: <https://www.ldn-cancer-project.uk/>

– North East and Cumbria Learning Disability Network

Standard 2: Inclusion and engagement

Improvement measures:

1. Trusts must demonstrate processes that ensure they work and engage with people receiving care, their families and carers, as set out in the NHS Constitution.
2. Trusts must demonstrate that their services are 'value-led'; for example, in service design/improvement, handling of complaints, investigations, training and development, and recruitment.
3. Trusts must demonstrate that they co-design relevant services with people with a learning disability, autism or both and their families and carers.
4. Trusts must demonstrate that they learn from complaints, investigations and mortality reviews, and that they engage with and involve people, families and carers throughout these processes.
5. Trusts must be able to demonstrate they empower people with a learning disability, autism or both and their families and carers to exercise their rights.

Standard 2: Inclusion and engagement

Improvement measure: Trusts must demonstrate processes that ensure they work and engage with people receiving care, their families and carers, as set out in the NHS Constitution.

Changing the system to fit the person

Louise is autistic and compulsively hoards at home. In 2018 Louise was brought into hospital, but sending her home with an Occupational Therapy assessment was difficult and the OT suggested that Louise's home needed a deep clean. Louise found this really difficult, so the Lead Nurse for Learning Disabilities worked with her to make her feel comfortable about having her home cleaned for her return.

In 2019 Louise was admitted back into hospital again while the Lead Nurse for Learning Disabilities was on leave. This time there was a breakdown in communication between Louise and the discharge team because although Louise presents as very capable, she was having extreme difficulty coping with the situation on her own.

In 2020 Louise was again admitted to hospital. The Lead Nurse for Learning Disabilities immediately arranged a meeting with Louise to make sure the plans for her discharge were less stressful. Concerns were raised again about Louise going home because of the cleanliness of her home and concerns about COVID-19.

Louise called the Lead Nurse in tears, because she had been told that if her home wasn't safe she would need to go into a nursing home which she did not want to do. The Lead Nurse advised Louise to get an independent advocate, and also arranged for Louise to meet with a cleaning team at her house before she was discharged, so that she could explain to them how she wanted her home to be cleaned, in preparation for her being able to go home. This helped greatly with Louise's anxiety.

– London North West University
Healthcare NHS Trust

Bringing good care to people

Vicky was in her early 30s when she started losing weight, and appeared lethargic and out of sorts. Her family took her to her GP who tried to take a blood sample. However, Vicky has a needle phobia and she was unable to sit still for the blood test. Support staff from Waddiloves Health Centre visited her at home, where Vicky's mum was fully involved in distracting and reassuring Vicky. Staff used a 'safe hold' technique and an Associate Practitioner was able to take her blood. Vicky was found to have anaemia and could start treatment. Vicky's mum has asked for any further blood tests to be done at home, where Vicky can be relaxed and her mum can be fully involved.

– Bradford District Care NHS Foundation
Trust

Valuing carers

At Kings Mill Hospital the Carers Charter explains what the hospital will do to help and support family carers. It says that family carers will be offered a Carer's Passport and identification card. It says they will be given help on how to care safely and information about support in the community.

Many people with a learning disability and complex health needs are cared for in the Respiratory Ward. The Respiratory Ward has bought a tea and coffee cupboard for parents and carers and some good quality sofa beds so that they can stay the night. They find that if you keep parents and carers happy, fed and watered they are instrumental in the person's care.

– Sherwood Forest Hospitals NHS Trust

Standard 2: Inclusion and engagement

Improvement measure: Trusts must demonstrate processes that ensure they work and engage with people receiving care, their families and carers, as set out in the NHS Constitution.

Adapting to change

ACE Anglia are a self-advocacy group in Suffolk who work closely with the Primary Learning Disability Liaison Team. During the COVID-19 pandemic the group have been meeting by Zoom and have had the opportunity to ask the learning disability nurses questions about a range of topics including keeping safe from picking up infection, testing for COVID-19, wellbeing, isolation, anxiety and disruptions to care and support.

The team has met virtually with a GP who talked about PPE, how to wear and dispose of masks, and what the GP surgery would look like when people came back in.

The Primary Learning Disability Liaison Team have sent out over 350 Easy Read packs to people with a learning disability about coronavirus.

– Norfolk and Suffolk NHS Foundation Trust

Finding new ways to meet people's needs

Patrick has a learning disability, but since a road traffic accident 10 years ago, his behaviour became challenging to those who cared for him. Patrick needed a CT scan of his head, and his paid supporters told hospital staff that he would only have a scan with heavy sedation.

Patrick received an appointment letter two days before his scan, which was not enough time to organise sedation. Cancellation is costly and Patrick may have had to wait a significant time before getting another appointment. The Lead Nurse for Learning Disabilities asked his supporters "What can we do differently that might allow this to go ahead?"

The Lead Nurse agreed with the CT technician for Patrick to be seen immediately on arrival, as any waiting time would increase his anxiety. Patrick wore his own clothes and wasn't asked to wear a gown. Patrick's supporter stayed with him at all times to explain what was happening and offer reassurance.

The scan was a success. Patrick had had many scans over the years and this was the first one he'd had without sedation. This meant he could go home immediately after his scan with minimal anxiety.

The department saved time and money by not having to offer sedation, as well as the additional staff this would have required, and significantly reduced Patrick's time spent in the department.

– Barts Health NHS Trust.

Anticipatory Care Calendars

Supporters at MacIntyre use Anticipatory Care Calendars to support people's access to Primary Health Care services. Over time, the Anticipatory Care Calendar picks up subtle changes in a person's behaviour or needs. This can help to accurately describe the change to the person's GP. Some professionals may have pre-conceived ideas about learning disabilities so that if you say "We're worried for Phillip because he's breaking furniture in his flat", they may think this is just what Phillip does. If you can evidence that this is new for Phillip, it may indicate that he is in pain, or confused or unhappy about something. You have written evidence to show what Phillip was like 6 months ago. GPs seem to appreciate this too, as it makes the investigatory process easier.

– Macintyre

Standard 2: Inclusion and engagement

Improvement measure: Trusts must demonstrate processes that ensure they work and engage with people receiving care, their families and carers, as set out in the NHS Constitution.

Seeing carers as an asset to the workforce

Family carers have been at the heart of developing Positive Behavioural Support (PBS) provision in Cumbria, where an Early Intervention scheme has been rolled out for pre-school children, school aged children and families. Family carers designed and delivered training for other families. Kelly's daughter is twelve and has a learning disability and is autistic. She says the PBS Early Intervention scheme has transformed her family's life. She recalls watching a documentary about Winterbourne View when her daughter was 3 years old and feeling sick with worry. Now after receiving experiential, peer-led training she feels more optimistic about her daughter's future.

The North East and Cumbria Learning Disability Network value the work that family carers do by paying them a fair wage for the work that they do, and investing in their training. One family carer is being supported to do a Masters level module in PBS with Northumbria University and there are plans currently being explored to recruit a family carer to be a Workforce Development Manager for families, paid in line with other Workforce Development Managers in the network.

– North East and Cumbria Learning Disability Network



Standard 2: Inclusion and engagement

Improvement measure: Trusts must demonstrate that their services are 'value-led'; for example, in service design/improvement, handling of complaints, investigations, training and development, and recruitment.

Value-led recruitment to the highest level

At Bradford District Care NHS Foundation Trust trained people with a learning disability interview all new members of staff whose job description specifies working with people with a learning disability. They devise questions and rank people's answers, and their interview is an important part of the overall recruitment process. The Trust has made it a requirement that these trained interviewers interview everyone who applies for a new post at Band 7 or above. This means that they have interviewed the Chief Executive and the Chair of the Trust. People with a learning disability are paid fairly for their time, just like anyone else would be for their work.

– Bradford District Care NHS Foundation Trust

Making the national work locally

University Hospitals Birmingham have recently launched their own learning disability standards based on the NHS learning disability improvement standards. The Birmingham standards act as a benchmark for good quality care for all autistic people and people with a learning disability across the trust. They use flow charts, checklists and reminders to bring the national standards to life in a way that makes them real for everybody in the Trust. This includes all staff and patients, so there is an easy read version too.

– Birmingham University NHS Foundation Trust

Space to speak up, and a mark of quality

The North East and Cumbria Access to Acute (A2A) Network. A network made up of the learning disability liaison nurses across the region meet regularly to progress regional strategic initiatives and hold a peer review session. Often they are only 1 or 2 acute liaison nurses in a trust so this can sometimes feel like an isolated role. The peer review session allows the nurses to come together and discuss best practice and challenges with their peers to come up with solutions and improve the lives of people with a learning disability. A lot of the regional work led by the network and the North East and Cumbria Learning Disability Network is born out of these discussions. One project which has been implemented across the North East and Cumbria is the Learning Disability Acute Care Diamond Standard Pathways and E-Learning. Acute trusts and their staff members will be awarded diamond status when a threshold has been reached and shows they are providing excellent care to people with a learning and their families.

– North East and Cumbria Learning Disability Network

Standard 2: Inclusion and engagement

Improvement measure: Trusts must demonstrate that they co-design relevant services with people with a learning disability, autism or both and their families and carers.

Making good use of Experts by Experience

Noami is an Expert by Experience at North Middlesex University Hospital. She supports with the development of the Learning Disability service. This opportunity empowers Noami to have a voice for herself as well as people with learning disabilities. She takes great pride in her role. She currently supports the service with activities such as training, quality checking, co-chairing the steering group meeting and being the voice of people with learning disabilities within the North Middlesex University Hospital.

North Middlesex Hospital have also set up a learning disability steering group forum meeting twice monthly where family members, social care providers, carers and people with learning disabilities meet with representatives from the Trust to discuss issues that affect the care of people with learning disabilities in the hospital. The steering group is an opportunity to find out what matters to patients and to work together to share ideas for making things better.

– North Middlesex University Hospital Trust

Responding to the needs of the local community

There is a small but significant number of people with learning disabilities who come into adulthood with needle phobias. The carer's forum at Barts Health NHS Trust raised the idea of a weekly dedicated phlebotomy clinic just for people who struggle to have blood tests. In response the clinic was developed and now offers a bespoke service

to the person. It starts with an assessment visit where the Lead Nurse for Learning Disability thinks about how the person communicates and make reasonable adjustments. She will consider a range of things, can people sit still long enough for the test, will they allow the phlebotomists to get close to them and to touch them and finally if will they tolerate equipment.

– Barts Health NHS Trust

Making care more dignified

On the Isle of Wight, the Epilepsy Specialist Nurse (Learning Disabilities) worked in conjunction with people with learning disabilities and their family and carers to understand about the care and treatment they receive for their epilepsy.

One of the areas highlighted was the need for the ambulance service to be able to carry and administer oromucosal Midazolam as a rescue medication for people with epilepsy. Up to this point they could only administer rectal Diazepam. People with a learning disability who required this intervention said that if they had a choice they would prefer Midazolam as it was more effective and dignified method of administration.

The Epilepsy Specialist Nurse took this information and worked closely with the lead pharmacist and ambulance service to develop a protocol to enable this treatment to be offered. This took a lot of liaison work but the result is now that the Isle of Wight ambulance service do now carry Midazolam and can administer to all people with epilepsy.

– Isle of Wight NHS Trust

Standard 2: Inclusion and engagement

Improvement measure: Trusts must demonstrate that they co-design relevant services with people with a learning disability, autism or both and their families and carers.

Peer training and awareness

Be Cancer Aware is a co-produced peer education programme supported by the North East and Cumbria Learning Disability Network. People with learning disabilities share information in their communities about a range of issues to do with cancer including signs and symptoms, risk reduction and screening. They use a variety of methods, personal stories, videos, games and discussion. The team is made up of representatives from a variety of community and voluntary sector organisations and no two trainers work in quite the same way, as each uses their own unique skills and interests to deliver the material.

Since the beginning of the COVID-19 pandemic, the groups work has moved to Zoom and has been adapted to include Zoom quizzes for self-advocacy groups and video materials that can be shared online. People with learning disabilities have reported that it is reassuring to be able to talk honestly about cancer and how it has affected them and their families.

– North East and Cumbria Learning Disability Network

Health Experts

The Waddiloves Health Experts Group started out when a group of people with learning disabilities came together on a healthy eating and exercise course, supported by learning disability nurses and other health professionals at their specialist learning disability health centre. Once the course was finished the group decided to keep meeting up and now get together 4 times a year. They discuss current issues in healthcare for people with learning disabilities, then have a question and answer session with a member of the team, such as podiatry or the ECG specialist. They check any easy read information about health that the Trust is putting out and consult on a range of accessibility issues for patients with learning disabilities.

– Bradford District Care NHS Foundation Trust



Standard 2: Inclusion and engagement

Improvement measure: Trusts must demonstrate that they learn from complaints, investigations and mortality reviews, and that they engage with and involve people, families and carers throughout these processes.

Involving people in the response to complaints

The Health Experts Group at Waddiloves heard from other people with a learning disability that the standard out of hours voicemail message that Trust staff were using was confusing and this was leading to patients avoiding calling for help out of hours. The Health Experts Group wrote a more accessible script, which is now used on all out of hours voicemail messages across the Trust. The Trust is no longer receiving complaints about its out of hours message being complicated.

– Bradford District Care NHS Foundation Trust

Learning from past poor treatment

When Eric was in his twenties he had severe toothache for several days. He went to his mainstream dentist who pulled the wrong tooth out, leaving him in severe pain. This continued over the course of 5 visits, with 5 wrong teeth pulled and Eric in pain the whole time. Understandably this left Eric with a severe phobia of the dentist. Eric is now in his early 40s and staff at Waddiloves Learning Disability Health Centre have been working with him slowly and consistently over time to reduce his fear of the dentist. He is less afraid than he was, but he still won't go in the chair. He is now involved in training mainstream dentists, specialist dentists and student nurses so that lessons can be learnt both from his traumatic past experience, and his gradual recovery.

– Bradford District Care NHS Foundation Trust

Expert care for the most critical cases

National research and mortality reviews have consistently highlighted the risk of respiratory illness to the life of people with a learning disability, especially those who also have complex physical health needs.

At Kings Mill hospital, the charge nurse on the respiratory ward has specific skills relevant to people with a learning disability and complex health needs, such as being able to manage and access patients' portacaths, implanted devices that allow easy access to the blood.

Over several years, the respiratory team have developed a pathway that means patients with a learning disability and complex needs come straight to the respiratory ward, where staff are highly trained and know many local people and families well. They have treated several patients who have lived happily and comfortably for years beyond their life expectancy and have a track record of successfully turning care around for patients who are critically ill on admission.

– Sherwood Forest Hospitals NHS Trust.

"People with a learning disability, autistic people, and families are experts in their own lives. It makes no sense not to involve them as equal partners in co-design."

Standard 2: Inclusion and engagement

Improvement measure: Trusts must be able to demonstrate they empower people with a learning disability, autism or both and their families and carers to exercise their rights.

A contract of care

Will is autistic. When Will became ill he needed to be admitted to hospital. Will is very comfortable with understanding information about his care, but needs significant reasonable adjustments to allow him to access treatment, around his sensitivity to noise and how he needs preparations to be made. Will was coping with depression and family issues when he became ill and soon felt that his care was being dictated to him by his consultant. Will and his consultant just didn't understand each other.

The Lead Learning Disability Nurse at London North West University Healthcare NHS Trust was asked to speak to Will. At this time, her role did not specifically cover autistic patients, but she was identified as the best person to support Will. The lead nurse sat down with Will and set out what treatment he needed. She supported him to create a contract for his consultant about how this would happen. This gave Will responsibility and power over his care and meant that he didn't feel that the doctors were pushing him. She helped Will to build up relationships around himself and include those important to him in creating a plan for his recovery over 3 months in hospital.

Will was successfully treated and recently contacted the lead nurse to tell her he was back at his university studies which are going well.

– London North West University
Healthcare NHS Trust

Empowering people with information

When Faye was 18 she had a phobia of needles and was refusing to have her annual health check. A learning disability nurse met with Faye at home. The learning disability nurse explained the annual health check and went through some options that Faye could use to overcome her phobia. Faye decided she wanted to use desensitization therapy. Faye created her own personalised desensitization pack about having a blood test, with help from the learning disability nurse. Unfortunately, when the day came for Faye's blood test, the phlebotomist who had liaised with the learning disability nurse had not shared information about Faye and the team showed her a lack of compassion and understanding when she arrived. Faye was understandably upset about this failed attempt, but her learning disability nurse included her in escalating their concerns to the nurse in charge, and arranged for the phlebotomy team to have more training in reasonable adjustments. With a few more tweaks, such as numbing cream for Faye's arm, Faye was able to try again and successfully had her blood test and annual health check.

– Bradford District Care NHS
Foundation Trust

Standard 2: Inclusion and engagement

Improvement measure: Trusts must be able to demonstrate they empower people with a learning disability, autism or both and their families and carers to exercise their rights.

Healthy Me Promotion Day

The Health Facilitation and Acute Liaison Service along with colleagues from the Community Learning Disability Team at Broom Street Community Unit held a Healthy Me Promotion Day. This aimed to empower people with a learning disability by promoting knowledge of their rights to an annual health check and a health action plan from their GP. People with a learning disability, families and carers were invited to meet with a wide range of teams including the Health Facilitation Team, Physiotherapists and Occupational Therapists and the Psychology Team. External providers included the Diabetes Team, Dental Care Team, Abdominal Aortic Aneurism Team, Breast and Bowel Screening Teams and the local Shared Lives Team. Practical demonstrations were offered and people with a learning disability had baseline health screening on the day. A wide range of people, family and carers attended. Health screening services in the area improved the range of reasonable adjustments they offer as a direct result of the event and primary care clinicians reviewed their own service delivery pathways to include more training and awareness for their staff teams.

– North Staffordshire Combined Healthcare NHS Trust



Standard 3: Workforce

Improvement measures:

1. Based on analysis of the needs of the local population, Trusts must ensure staff have the specialist knowledge and skills to meet the unique needs of people with a learning disability, autism or both who access and use their services, as well as those who support them.
2. Staff must be trained and then routinely updated in how to deliver care to people with a learning disability, autism or both who use their services, in a way that takes account of their rights, unique needs and health vulnerabilities; adjustments to how services are delivered are tailored to each person's individual needs.
3. Trusts must have workforce plans that manage and mitigate the impact of the growing, cross-system shortage of qualified practitioners with a professional specialism in learning disabilities.
4. Trusts must demonstrate clinical and practice leadership and consideration of the needs of people with a learning disability, autism or both, within local strategies to ensure safe and sustainable staffing.

Standard 3: Workforce

Improvement measure: Based on analysis of the needs of the local population, Trusts must ensure staff have the specialist knowledge and skills to meet the unique needs of people with a learning disability, autism or both who access and use their services, as well as those who support them.

Facilitating relationships with mainstream healthcare teams

Teresa came to the hospital as a day case for some gastrointestinal support. Teresa was really scared as she'd had bad hospital experiences in the past. The acute liaison nurse went out to meet Teresa at her home. They had their second meeting in the café area of the hospital. The next time Teresa came into the hospital she sat with a nurse from the Gastrointestinal Day Case Team. They hit it off instantly and Teresa felt really comfortable with her. The nurse walked Teresa down to the ward and they went into the doctor's room to have a look around. Teresa was so relaxed at that point that they could have attempted some of the interventions needed, but the team took the decision not to push it too far. They made an appointment for Teresa to come back when the nurse she had met was next on shift. Teresa came back in and had everything done happily.

– Nottinghamshire Healthcare NHS Foundation Trust



Knowing when specialist services are best

Gill was in her 60s when she was referred to a psychiatrist due to severe changes in her behaviour, such as hurting other people, refusing to go out and becoming scared of familiar places. Gill was also refusing to go to her normal optician. She went to Waddiloves Learning Disability Health Centre for a range of basic health checks, including for her vision. The orthoptist carried out the assessment with help from a learning disability nurse. Gill was found to have cataracts in both eyes which was reducing her vision. After appropriate surgery her vision is now much better. Gill has started acting like herself again, she no longer lashes out due to fear and does not require treatment from the psychiatrist.

– Bradford District Care NHS Foundation Trust

"People with a learning disability and autistic people are equal members of society, who use healthcare services just like anyone else. Having a skilled staff team that has specialist knowledge enables people to access these services."

Standard 3: Workforce

Improvement measure: Based on analysis of the needs of the local population, Trusts must ensure staff have the specialist knowledge and skills to meet the unique needs of people with a learning disability, autism or both who access and use their services, as well as those who support them.

Expertise embedded across services

At Kings Mill Hospital there are learning disability champions in various departments including in the Emergency Department, the therapy department and the eye care department. There is a learning disability nurse working in the End of Life Team who works to make sure people with a learning disability have a respectful death and also teaches other staff how to recognise when people with a learning disability are approaching end of life. Having expertise threaded through every area of the hospital makes it less likely that people with a learning disability and autistic people will be automatically referred back to the Lead learning disability nurse when they could be treated more appropriately by another specialist.

– Sherwood Forest Hospitals NHS Foundation Trust

The best possible care given without assumptions

Kwame lived in supported living and his diabetes was not being managed well. When Kwame was admitted to hospital with serious complications, he was told that he needed to be in a nursing home where his diabetes could be managed. From getting to know Kwame and his support staff, the lead nurse for learning disabilities did not believe that the problem with Kwame's diabetes was down to the support he was having. She fully investigated this, including visiting Kwame's home to observe practice there. Kwame didn't want to move, so the learning disability nurse stood alongside him and said that Kwame would not get better care at a nursing home until the underlying cause of his problem was identified and dealt with. Eventually, a specialist diabetic dietician was brought in and Kwame's problems with his diabetes were stopped and have been stable for several months. This meant Kwame was able to stay at home where he wanted to be.

– Barts Health NHS Trust

Standard 3: Workforce

Improvement measure: Staff must be trained and then routinely updated in how to deliver care to people with a learning disability, autism or both who use their services, in a way that takes account of their rights, unique needs and health vulnerabilities; adjustments to how services are delivered are tailored to each person's individual needs.

Including people's voices in nurse training

The Health Experts Group at Bradford District Care NHS Foundation Trust run a workshop session every year for nursing students from Bradford University who are on placement within the Bradford District Care NHS Foundation Trust. People with a learning disability and autistic people share their real life experiences of health care and what can be learned from those experiences. One member of staff has worked closely with a man who has complex health needs and doesn't use words to communicate, to create a video about him that is shown at the training sessions.

– Bradford District Care NHS Foundation Trust

Backing initiatives up with training

The Co-ordinate my Care pathway in London North West University Healthcare NHS Trust is a centrally accessible record about a person's care needs, ongoing treatment and any reasonable adjustments that they need. The initiative was embedded by the lead nurse for learning disabilities who trained a number of clinicians across the local healthcare landscape, including GPs across several boroughs, community learning disability nurses across 3 boroughs, and acute nurses and doctors. Efforts to train more healthcare professionals is still ongoing.

– London North West University Healthcare NHS Trust



A uniform approach to training

Through the North East and Cumbria Learning Disability Network and the Access to Acute (A2A) Network they have developed a regional set of Acute Care Pathways and E-Learning. The Learning Disability Diamond Acute Care Pathways look at planned and emergency admission and discharge and they are underpinned by core values and principles. These core values and principles make up the E-Learning training and are focused on Reasonable Adjustments, Communication, Mental Capacity Act and STOMP. The training is available to every member of staff working in the Acute Trust regardless of whether they are in a clinical or non clinical role. Every ward has been given a laminated set of pathways making it easy to provide consistency of care for every person with a learning disability within the large geographical area that the network covers.

– North East and Cumbria Learning Disability Network

Standard 3: Workforce

Improvement measure: Trusts must have workforce plans that manage and mitigate the impact of the growing, cross-system shortage of qualified practitioners with a professional specialism in learning disabilities.

Sharing resources

During the height of the first wave of the COVID-19 pandemic, Birmingham Community Healthcare NHS Trust visited the acute wards of University Hospitals Birmingham to help ensure that every person with a learning disability was seen at least once a week. This unexpected opportunity for collaborative working has been really helpful for sharing expertise, and has worked so well that the Trust are now looking at how they can commission this work to continue in the long term.

During the crisis, patients with a learning disability were allowed visitors and could have a carer to stay with them if needed. Staff delivered activity packs to ensure that anyone who was alone was occupied. The hospital bought iPads for all the wards so that people could video call with family or watch films. Sensory boxes were bought for the Emergency Department to help reduce anxiety for patients.

As awful as the situation was, staff rose to the occasion and managed to improve resources wherever they could.

– University Hospitals Birmingham NHS Trust and Birmingham Community Healthcare NHS Trust

Liaising between patient and staff

Harry was in his early 20s when he had 2 failed admissions to the acute hospital for dental treatment under general anaesthetic. Harry has a learning disability and is autistic and his mum usually supported him with his health care. Harry's dentist requested that Harry's learning disability nurse go to the pre-op clinic. The nurse gathered information and created a support plan with Harry and

his mum. She shared this information with the ward and with Harry's anaesthetist. When Harry was admitted she went to the ward and made sure everyone had read his plan and understood how Harry needed to be supported. Harry was safely anaesthetised and had his treatment, while the learning disability nurse supported his mum who was understandably anxious and worried.

– Bradford District Care NHS Foundation Trust

Finding connections in unusual places

Richard is autistic and was discharged from hospital during the COVID-19 pandemic. In order to go back to his home with a residential care provider he needed to go through a 2-week isolation period. Richard's mom, Kathy, was really worried about how he would cope with this as she knew it would make him extremely anxious. Kathy brought Richard home with her to self-isolate, and ended up calling the lead nurse for learning disabilities late one evening for reassurance. The learning disability nurse was able to chat things through with Kathy and eventually Richard did go into isolation at his home, but in a way that he could cope with. Kathy is also a nurse at the hospital, and as a result of speaking to the learning disability nurse decided to take a proactive role on her own ward to improve care for autistic patients. She has been instrumental in setting up a sensory room and inspiring other nurses to become learning disability champions.

– Nottinghamshire Healthcare NHS Foundation Trust

Standard 3: Workforce

Improvement measure: Trusts must have workforce plans that manage and mitigate the impact of the growing, cross-system shortage of qualified practitioners with a professional specialism in learning disabilities.

Robust training for Learning Disability Champions

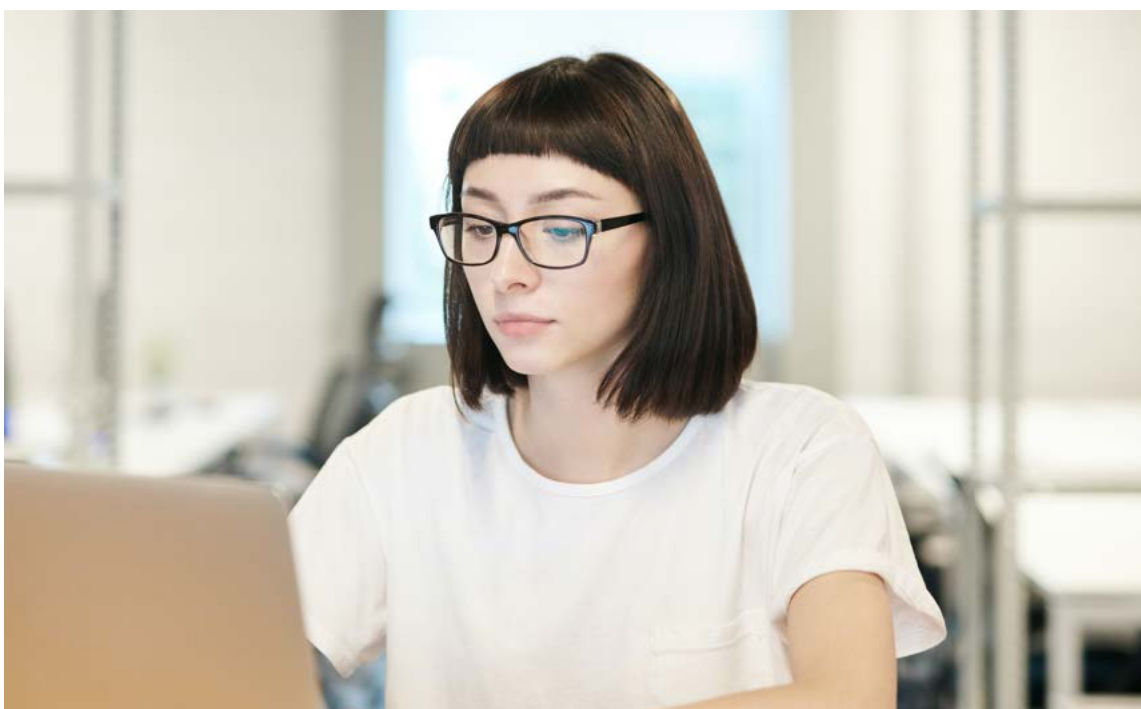
The Health Facilitation and Acute Liaison Service in North Staffordshire run a Learning Disability Champion Scheme, which promotes the 4 L's that are the keystone to any learning disability champion's practice. These are Listening, Learning, Liaising and Leading. All learning disability champions receive a half-day training package which is jointly delivered with an Expert by Experience. To date the team have inducted more than 160 learning disability champions across the acute hospital and primary care service and aim to develop this further into Secondary and Mental Health services. They hope that eventually all champions will have an annual training update, and that there will be a learning disability champion in every local healthcare service.

– North Staffordshire Combined
Healthcare NHS Trust

Making it easy to get off to a good start

The Lead Nurse for Learning Disabilities at Barts Health NHS Trust has put a poster up in various places across the hospital with a checklist of what staff need to do if they come across a person with a learning disability. This includes checking if the person is flagged as having a learning disability on the system, asking for a hospital passport, ensuring reasonable adjustments are made, involving family and carers and considering whether a Mental Capacity Assessment is appropriate. Any member of staff, regardless of their experience of caring for people with a learning disability or autistic people should be able to follow the checklist and provide a basic level of good care. The checklist is followed up by contacts for specialist learning disability nurses that staff can contact for further support.

– Barts Health NHS Trust



Standard 3: Workforce

Improvement measure: Trusts must demonstrate clinical and practice leadership and consideration of the needs of people with a learning disability, autism or both, within local strategies to ensure safe and sustainable staffing.

A network for Acute nurses

Many acute liaison nurses work alone within a hospital or even a trust and may not be managed by someone with a learning disability specific qualification. Access to Acute networks (A2A) provide a forum for acute nurses from a wider geographical area to meet with their peers, discuss learning and troubleshoot common problems.

In the North East and Cumbria, the A2A Network is part of the North East and Cumbria Learning Disability Network. It exists to capture and disseminate learning from individual Acute Trusts across the region, have a standardised approach to the care of people with a learning disability across the region, have an innovative and creative work programme to improve the lives of people with a learning disability when accessing acute services and provide a support network in which the acute liaison nurses can develop their practice.

– North East and Cumbria Learning Disability Network

Regular oversight from senior leadership

At Kings Mill Hospital the learning disability specialist nurse reports on measures to improve care for people with a learning disability every two weeks. This report is given to the medical director and the trust board. The trust board receive a report every three months detailing any deaths of people with learning disabilities in hospital.

– Sherwood Forest Hospitals NHS Foundation Trust

At Bassetlaw Hospital, the Associate Nursing Director takes an active role in driving up quality for patients with a learning disability. He takes a lead in putting strategies in place and ensuring buy in from across the hospital. This includes offering Tier 2 learning disability training widely, with Tier 3 training where staff are ready to progress further.

– Nottinghamshire Healthcare NHS Foundation Trust

Capitalising on expertise within the team

At a Trust Conference, the Clinical Chair for Women's and Children's services at Kings Mill and the Charge Nurse on the Respiratory Ward met and spoke about the care of patients with a learning disability and complex health needs who were transitioning from children's to adult services. The charge nurse had clinical skills that are specifically suited to patients with complex health needs and between them they decided that he would take responsibility for a small group of patients who would benefit from his clinical skills. Along with the Respiratory Consultant at Kings Mill, the Clinical Chair and charge nurse developed a pathway that works extremely well for patients with complex health needs and regularly liaise together to ensure a smooth handover for children with complex health needs who are transitioning into adulthood.

– Sherwood Forest Hospitals NHS Foundation Trust

Standard 3: Workforce

Improvement measure: Trusts must demonstrate clinical and practice leadership and consideration of the needs of people with a learning disability, autism or both, within local strategies to ensure safe and sustainable staffing.

A framework that changes people's lives

Sunderland's Primary Care Self-Assessment Framework was developed to ensure that all GP practices in Sunderland offer excellent care to people with a learning disability. Sunderland CCG have recently been awarded exemplar status for their innovative practice.

One of the objectives of the framework is to ensure that patients who are nervous about investigations such as blood tests and hearing screening are referred to a point of care clinic provided by learning disability nurses and support workers.

Rita is in her 60s has a long standing fear of health interventions. The clinic spent time with Rita, developing a relationship to the point where she felt comfortable having a blood test. It was discovered that Rita had high cholesterol and needed some changes to her medication and lifestyle. She also had an ear examination which showed hearing loss in both ears and a growth in her Eustachian tube, which thankfully turned out to be benign.

As a result of Rita's experience, the Gold standard of the Self-Assessment Framework requires GP surgeries to refer all patients over the age of 55 to the health promotion team for an ear examination and hearing screening.

– Cumbria, Northumberland, Tyne and Wear NHS Foundation



Standard 4: Specialist learning disability services

Improvement measures:

1. Trusts must have plans for the development of community-based intensive support, including treatment and support for people accessing mental health services and the criminal justice system.
2. Trusts use the care and treatment review (CTR) and care and education treatment review (CETR) to ensure a stringent assessment is made if admission is anticipated or requested, and that discharge arrangements ensure no individual stays longer than necessary.
3. Trusts have processes to regularly review the medications prescribed to people with a learning disability, autism or both. Specifically, prescribing of all psychotropic medication should be considered in line with NHS England's programme stopping over medication programme STOMP.
4. Trusts providing inpatient services have clinical pathways that adhere to evidence-based assessment and treatment, time-limited interventions and measurable discharge processes to ensure inpatient episodes are as short as possible.
5. Trusts have governance processes for measuring the use of restraint and other restrictive practices, including detailed evidence-based recommendations to support the discontinuation of planned prone restraints and reduction in unwarranted variation in use of restrictive practices. They can demonstrate that alternative approaches are being deployed.

Standard 4: Specialist learning disability services

Improvement measure: Trusts must have plans for the development of community-based intensive support, including treatment and support for people accessing mental health services and the criminal justice system.

Mental health support during COVID-19

The Green Light Team in Norfolk and Suffolk support people with a learning disability who have experience of mental health difficulties in the community. When the COVID-19 pandemic started the team quickly adapted their forums so that people could keep in touch over Zoom on a regular basis. There was a lot of initial set up, with the team producing easy read materials and finding video demos on YouTube about how to get onto video calls. The team delivered these to people with a learning disability, families and carers. Over time the number of online attendees has grown from 6 to 20, and the group have also decided to meet weekly rather than monthly to ensure everyone has the peer support they need during this stressful time.

Conversations vary from coping mechanisms for anxiety and depression or the hows and whys of wearing a face covering in public, to quizzes, fun and games that allow people to keep friendships going while they are self-isolating. The team have been delivering activity packs to members' homes with cookery ideas, crafts and exercises.

Through the online meetings some people have been fast tracked to receive mental health services or access their GP and many members have made new friends during lockdown.

– Norfolk and Suffolk NHS Foundation Trust

Recognising the importance of early help

The Cumbria Early Intervention Project was developed with the idea of providing families with a range of support to enable them to use Positive Behavioural Support tools from a very early age, well before any significant difficulties are faced around behaviour that challenges. The pilot project consisted of Early Positive Approaches to Support (E-PAtS) for children aged 5 and under, PBS for school-age children and resilience training for family carers with children of any age. This was complemented with a co-produced early intervention strategy with strong family carer involvement. This was the first approach of its kind that took a variety of measures at the same time and actively targeted families whose children had not yet necessarily shown behaviours that challenge.

The project was a success and is now being rolled out across the whole of the North East and Cumbria Learning Disability Network, to ensure that families are equipped with the resources they need to support their loved ones.

– North East and Cumbria Learning Disability Network

Standard 4: Specialist learning disability services

Improvement measure: Trusts must have plans for the development of community-based intensive support, including treatment and support for people accessing mental health services and the criminal justice system.

A dedicated service where one is needed

Bradford District Care NHS Foundation Trust is the only Trust in England with a fully dedicated learning disabilities health centre, called Waddiloves. In 1998 a large institution in the area was disbanded and several people with a learning disability started to live more independently in the community. However, it soon became apparent that community teams weren't meeting the needs of people in some areas of health such as dentistry and podiatry. The learning disability health centre was set up to meet this need and is now the base for community learning disability nurses, as well as offering a range of health clinics. People are encouraged to use mainstream services where possible, and some people only use Waddiloves for specific services that they struggle with. Many people start by coming to Waddiloves, and with the gradual support of the team, make the move over to accessing mainstream services.

– Bradford District Care NHS Foundation

"People with a learning disability and autistic people have a right like anyone else to live in the community. Specialist services play an important role in enabling people to live well rounded independent lives."



Standard 4: Specialist learning disability services

Improvement measure: Trusts use the care and treatment review (CTR) and care and education treatment review (CETR) to ensure a stringent assessment is made if admission is anticipated or requested, and that discharge arrangements ensure no individual stays longer than necessary.

Sharing knowledge

At the start of the COVID-19 pandemic, the acute liaison nurse at Bassetlaw was drafted in to help with some Care and Treatment Reviews. As an acute nurse she shared ideas and knowledge about how physical health can impact upon someone's behaviour and shared some non-verbal pain scales that she finds helpful for supporting people who don't use words to communicate. She also gave insights on how she records and shares information about people's support between teams that will help with people's transitions from inpatient setting to home.

– Nottinghamshire Healthcare NHS Foundation Trust



Standard 4: Specialist learning disability services

Improvement measure: Trusts have processes to regularly review the medications prescribed to people with a learning disability, autism or both. Specifically, prescribing of all psychotropic medication should be considered in line with NHS England's programme stopping over medication programme STOMP.

Finding alternatives to medication

Mary is autistic and has a learning disability. When the support relationship at her supported living home started to break down she was referred to learning disability nursing and psychiatry. A holistic nursing assessment and a review of Mary's behaviour charts showed that staff were not taking a consistent approach with Mary which was fuelling Mary's anxiety and frustration. The learning disability nurse advocated for Mary's benzodiazepine to be stopped and stepped in to liaise between adult services and Mary's family to make sure that Mary's needs were prioritised, and to refer the family to a carers service.

At the start of the national lockdown in March 2020 Mary was served notice to leave her supported living home. A placement was found for Mary to live in another city, away from her family and with very little opportunity to keep in touch with them due to the restrictions of lockdown and her own family's health needs. The learning disability nurse again advocated for Mary, raising her concerns to senior management, and eventually it was agreed that Mary could be supported by a local provider, where she is now happy and settled with highly skilled staff who understand Mary and her needs.

– Isle of Wight NHS Trust

Enabling people to lead their own care

Peter is 25 and lives at home with his dad. He had a difficult start to life, getting into trouble at his specialist school and eventually spent some time in specialist hospitals and rehabilitation services, until eventually he was given the right support, space and independence to enable to move back home with his father.

Peter was on anti-psychotic medication, which meant that he couldn't take on a job that he wanted, working in a garden, as he couldn't handle machinery while on the medication.

Peter attended a pharmacy led clinic and was adamant that he wanted to come off his medication. He felt he was in a better place, and it was the right time to choose the life he wanted, where he felt valued and could do something he enjoyed.

The team agreed to gradually reduce Peter's medication and eventually Peter was drug free, just having outpatient appointments to check up on how he is doing. Peter's life has changed completely. He is in the job he wants to do, working outside in the gardens and has joined a local gym, taking pride in his physique and appearance.

– Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust

Standard 4: Specialist learning disability services

Improvement measure: Trusts have processes to regularly review the medications prescribed to people with a learning disability, autism or both. Specifically, prescribing of all psychotropic medication should be considered in line with NHS England's programme stopping over medication programme STOMP.

Learning to understand Eddie

Eddie has cerebral palsy and a learning disability and doesn't use words to communicate. He lives in a residential home with support. Eddie was on risperidone for several years, but it was found that there was no clear reason for this, and Eddie did not have any mental health difficulties.

The Community Learning Disability Team found that it seemed as though the risperidone was prescribed to manage behaviour that other people found difficult such as grabbing and moaning.

Eddie was seen by a psychiatrist, with a plan to increase his medication to manage this behaviour. However, the psychiatrist instead asked the Positive Behaviour Support (PBS) team to assess Eddie's behaviour, and found that his grabbing and moaning were Eddie trying to communicate.

The PBS team trained Eddie's staff team to understand his behaviour and to find better ways of making sure he got what he needed, including Active Support and Intensive Interaction. As a result of this change in his support, Eddie worked to become medication free. He is now more alert and energetic and enjoys swimming and football. His relationships with the people around him have improved.

– Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust

"People with a learning disability and autistic people should not be over medicated. They have a right to be supported to have access to non-drug therapies and other practical support."

Standard 4: Specialist learning disability services

Improvement measure: Trusts providing inpatient services have clinical pathways that adhere to evidence-based assessment and treatment, time-limited interventions and measurable discharge processes to ensure inpatient episodes are as short as possible.

Circles of Support

Circle of Support meetings led by the Lead Nurse for Learning Disabilities and Autism alongside the patient's Circle of Support, were introduced by the London North West University Healthcare NHS Trust in 2018, for anyone with a learning disability, autism, or both, admitted for more than five days. This means that the person's progress can be reviewed, treatment can be planned and the right kind of support can be put in place before the person goes home. It also makes sure that people do not stay in hospital for any longer than is necessary.

– London North West University
Healthcare NHS Trust

Retaining links with community teams

When Rachel was first admitted to an Assessment and Treatment Unit she did not have any of her own clothes with her and she was too nervous to leave her room. Rachel was extremely worried as she thought she would be given covert medication in her food. Rachel's community learning disability team kept up their links with Rachel and visited her to bring her clothes and reassure her. Rachel's community learning disability nurse encouraged Rachel to come out of her room and walked around the unit with her to familiarise her and introduce her to some people there. Rachel was quite quickly ready for discharge, and feels confident about coming home with the continued support of the Community Learning Disability Team.

– Barnet, Enfield and Haringey Mental
Health NHS Trust



Standard 4: Specialist learning disability services

Improvement measure: Trusts have governance processes for measuring the use of restraint and other restrictive practices, including detailed evidence-based recommendations to support the discontinuation of planned prone restraints and reduction in unwarranted variation in use of restrictive practices. They can demonstrate that alternative approaches are being deployed.

A whole system PBS approach

When the North East and Cumbria Learning Disability Network decided to implement a Positive Behavioural Support (PBS) approach to workplace transformation they discovered that the term PBS was being used in a variety of ways by different practitioners, with varying success.

They set out with the aim of having one gold standard for PBS across the whole region, that uses a cascade model to ensure that evidence based practice is filtered from strategic level to everyday practice.

They have teamed up with Northumbria University to set up a practice leaders programme at Masters level, and have trained several practice leaders in social care organisations. They are running further courses at lower levels for PBS facilitators, and are rolling out the practice leadership model to NHS providers too, including 2 large mental health Trusts who run secure services for people with a learning disability.

Practice leaders who have taken the PBS course have now formed a PBS coalition that focuses on continued support and development post qualification. The organisations involved have seen benefits including value-based recruitment, increased staff retention and better quality of care for patients.

– North East and Cumbria Learning Disability Network



Changing Our Lives

Tel: 0300 302 0770

Email: ask@changingourlives.org

Web: www.changingourlives.org

Twitter: [@positive_lives](https://twitter.com/positive_lives)

Registered Charity Number: 1093883