

SHOW YOU  
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# Learning Disability and/or Autism Initiative 2021

**Provide**  
*community*

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# Vision

Our vision is for people with a Learning Disability and/or Autism to have the *same opportunity* as everyone else to live safe and *healthy lives* and to be treated with *dignity* and *respect*.





**A learning disability is different for every person who has one. There are some things that are common for everyone including a reduced intellectual ability and difficulty with everyday activities – for example; household tasks, socialising or managing money – which affects someone for their whole life.**

People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people. The level of support someone needs depends on the individual. For example, someone with a mild learning disability may only need support with things like getting a job. However, someone with a severe or profound learning disability may need full-time care and support with every aspect of their life – they may also have physical disabilities. It is estimated that 1.4 million people in the UK have a learning disability and around 350,000 have a severe learning disability.

# What is a *learning disability?*



# What is autism?

**Autism is a life-long condition that affects how people perceive the world and interact with others. People with autism see, hear and feel the world differently to other people. Autism is not an illness or a disease and often people feel that being autistic is a fundamental aspect of their identity. Autism is a spectrum condition-all autistic people share certain difficulties which will affect them in different ways.**

Autism can be diagnosed at any age and affects males and females. Common symptoms of autism are:

- Delayed or absent speech
- Problems listening, concentrating and understanding
- Frequent repetition of words and phrases
- Taking things literally
- Difficulty sensing and interpreting people's feelings
- Difficulty expressing feelings
- Over or under sensitivity to sound, touch, taste, smell or light
- Rituals or repetitive behaviours
- Disliking changes to routine
- Difficulty making friends and socialising

The National Autistic Society estimates that there are 700,000 people in the UK who have autism which accounts for 1.1% of the population. Around 40% of autistic people have a learning disability, compared with just 1% of people without autism. A clinical assessment is needed to diagnose learning disability (round 1 in 10 people with a learning disability are autistic). 3 in 10 autistic people speak few or no words.

Whilst this strategy recognises and understands that there is a formal diagnostic process for children and adults with a learning disability and/or autism, we are keen not to exclude individuals who have a learning difficulty and would support the need to take individual needs into account, although they do not necessary meet the formal criteria for diagnosis.

# Contents

*Click on the  
headings below  
to navigate to the  
relevant section...*



<b>1</b>	<b>Introduction</b>	06
<b>2</b>	<b>What you told us!</b>	10
<b>3</b>	<b>National Policy and influences</b>	11
<b>4</b>	<b>Essex Demographics</b>	18
<b>5</b>	<b>Where do we want to be?</b>	21
<b>6</b>	<b>Action Plan</b>	22
<b>7</b>	<b>Our Stories</b>	29

*Click here to go to  
the next page*

# Introduction



**This strategy sets out a clear vision on how we can work differently and more effectively to improve the lives of individuals who have a learning disability, and or autism, who are part of our community and come into contact with our services. The aspirations of and for people with learning disabilities and/or autism are, unsurprisingly the same as the rest of us, to be listened to as individuals, to have choices about the way they live their lives, and to enjoy good health.**

In developing this strategy, we want to ensure that people receiving treatment, care and support from us, whether that be because of another health concern, a learning disability or autism, do not encounter inequalities and that our staff have the skills and knowledge to help them identify when a person has a learning disability and or autism, so they can be proactive in addressing those care and support needs. This may be a process of engaging with the individuals, families or carers and our partners so that we can respond appropriately and when necessary by making reasonable adjustments. Making reasonable adjustments is mandated in the Equality Act 2010 and requires bodies to make reasonable adjustments for disabled people and to ensure that disabled people do not face 'substantial disadvantage' but it is also about delivering person-centred care, adjusting our normal practice so that everyone gets the care and treatment they need and nobody is disadvantaged because they have a disability. This, alongside other adjustments, could include longer appointments so that the individual has the opportunity to communicate and understand information given to them which may be an easy read format so they can make informed decisions about their care and support (Appendix 1).





The UK government supports the **social model** as a way of understanding disability. This model, unlike the medical model says that disability is not caused by an individual's health condition or impairment, but by the way that society treats and creates barriers for people with health needs. The barriers generally fall into three categories:

- a. The environment – including inaccessible buildings and services;**
- b. People's attitudes – stereotyping, discrimination and prejudice;**
- c. Organisations – inflexible policies, practices and procedures.**

Using the social model enables individual practitioners and wider society to identify the barriers that prevent disabled people from fully participating in society or experience disadvantage compared to non-disabled people. The social model is also supported by disabled people and encourages society to become more inclusive.

We know there are parts of the health and social care services, as well as other organisations and individuals that are making a real effort to address the problems of access to equal support and healthcare for people with a learning disability or autism. More than 200 healthcare organisations have signed up to the 'Get it Right' charter. There are also some areas of good practice and key individuals, such as specialist liaison nurses, which are excellent examples of good practice. However, equal healthcare is a legal obligation that should be embedded in the everyday running of the health and social care services, in every GP practice and in every hospital ward, not an exercise in identifying pockets of good practice.

A particular area of concern is the transition process between children and adult services. Alongside physical and emotional changes that are part of growing up, the majority of children with a learning disability and or autism will encounter a process of moving from children services to adult. The reality of this is that the two services have very different cultures and are organised in an entirely different way. The transition process usually starts around the age of 16 and can continue until the individual leaves school and up to the age of 25. During this time the child and their families need to be supported to negotiate the systems, identify future aspirations, and set realistic goals for the future including education and work opportunities. Transitions can be a very challenging time for families on many levels and needs to be individualised and recognised as a process and a series of events rather than a one off event, which for some will take significantly longer than others.



The staff interviewed as part of the development of this strategy, both within Provide and other agencies, identified transitions as the most challenging time for both staff trying to navigate the systems and for the young adults moving through the services. There is a very clear need for an expert in this area both to support staff and young people during this process in order to improve the experience for the service user and get the best outcome.

For adults, we have seen some shocking and concerning examples of abuse and poor care and support through the Winterbourne review and more recently at Muckamore Abbey in Northern Ireland. Also, some ten years ago Mencap launched 'Death by Indifference' a campaign which highlighted the poor treatment of adults with a learning disability in the NHS and triggered an independent inquiry 'Healthcare for All' (2008) which concluded that people with a learning disability were finding it much harder to access good quality healthcare. Sadly, the persistence of health inequalities faced by people with learning disabilities is still evident. People with learning disabilities still die on average 15–20 years sooner than people in the general population, some of those deaths potentially amenable to good quality healthcare.

The Learning Disabilities Mortality Review (LeDeR) programme was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives. It is being implemented at the time of considerable spotlight on the deaths of patients in the NHS, and the introduction of the national Learning from Deaths framework in England in 2017. The programme is led by the University of Bristol and commissioned by the



Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.

National Guidance on Learning Disability Deaths was published in March 2017 and provides a framework for NHS Trusts for identifying, reporting, investigating and learning from the deaths of people in their care. The guidance also requires providers to have a clear policy for engagement with bereaved families and carers and an updated policy on how they should respond to and learn from the deaths of patients who die. Trusts have to collect and publish this data on a quarterly basis.

Our ambition in developing this strategy includes talking to all our staff and working together with the people who use our services, both children and adults, their families and key partners. Together, we shape this strategy so that it is fit for the future and will improve outcomes for the individuals concerned whilst paying particular attention to ensuring those individuals have choice and control of their support and treatment options. This strategy will also take a proactive view of reviewing our approach to people with a learning disability and/or autism, where necessary improving services in order to address and implement the key outcomes of the national guidance, and in particular the review of premature deaths. In doing so will also focus on improving our services by promoting good health and wellbeing.



## SHOW YOU KNOW



Introducing...

**Suzy** ↑

**We wanted to have as much service user engagement as possible when developing this strategy and we thought to create a design competition for our new logo.**

We asked our service users to help us design a badge for our Learning Disability and/or Autism strategy, explaining that the badge will be worn by our staff to demonstrate that they have read and understood this new strategy and are able to offer appropriate help and support. From the submitted designs we received, our team chose our top three designs and then asked service users and carers to vote on their top favourite designs.

We would like to give a big shout out and a massive thank you to Susan Docksey who designed the logo. In honour of the badge design competition winner, the team decided in naming the hedgehog, Suzy after its creator. Suzy will be the symbol for this exciting new Learning Disability and/or Autism Initiative.

All staff will receive training on this new initiative. Once the training is complete, each member will receive a badge, demonstrating their awareness of the objectives within the Learning Disability and/or Autism Strategy and that these Provide employees are approachable for anyone who has any queries about this initiative.





# What you told us!



People with learning disabilities who are receiving services from Provide told us that they wish to have choice over all aspects of their lives and want to be supported to have the same opportunities as everyone else, to be independent and their views to be respected. Some of the main points:

- a.** Seeing the same person at appointments helps to build relationships, trust and is very important.
- b.** I need time to explain things properly.
- c.** I want to be listened to.
- d.** Friendships and family are important and matter to me.
- e.** Staff leaving sometimes has an impact on me.
- f.** I value my voluntary work and would want to continue to do this.
- g.** I suffer from anxiety and stress and waiting in crowded areas increases this difficulty.
- h.** I need help to navigate the health and care system.
- i.** Children and young people need support to contribute to their care plans.
- j.** Using public transport can be a problem for me.
- k.** More help and support is needed through transition.
- l.** Some people may need help to maintain relationships.



# National Policy and influences



Over the last 15 years there has been a plethora of legislation and guidance to improve the outcomes for people with a learning disability and/or autism. Some of the most relevant legislation to developing this strategy is summarised here but this is by no means a conclusive list:

**2007 MENCAP 'DEATH BY INDIFFERENCE':** In March 2007, Mencap published 'Death by Indifference', which reported the deaths of six people with a learning disability – deaths that the six families involved and Mencap believe were the result of failings in the NHS. The report put the spotlight on the tragic consequences of the healthcare inequalities experienced by people with a learning disability. 'Death by Indifference' triggered an independent inquiry and an investigation of the six cases by the Parliamentary and Health Service Ombudsman. This resulted in the government accepting all the recommendations of the inquiry and setting out their delivery in the Department of Health strategy for people with a learning disability, Valuing People Now.

**2008 SIR JONATHAN MICHAEL PUBLISHED 'HEALTHCARE FOR ALL' – INDEPENDENT INQUIRY INTO ACCESS TO HEALTHCARE FOR PEOPLE WITH LEARNING DISABILITY.** An independent inquiry into access to healthcare for people with learning disabilities was established under Sir Jonathan Michael's leadership in May 2007, following the publication of the Mencap report 'Death by Indifference', which described the experiences of six people who died whilst under the care of the NHS. The Disability Rights Commission Formal Investigation into equal treatment had also raised questions about the quality of healthcare for people with learning disabilities who were physically ill.

**2009** The Government publishes **VALUING PEOPLE NOW** – the Government's plan to improve the lives of people with learning disabilities and their families. It covers all aspects of life, including health, housing, getting a paid job, personalisation, transition, advocacy, hate crime and relationships.



The strategy has a focus on employment, health and housing. All people with a learning disability are people first with the right to lead their lives like any others, with the same opportunities and responsibilities, with the same dignity and respect. This strategy is inclusive of those groups who are least often heard and most often excluded.

**2009 PARLIAMENTARY AND HEALTH SERVICE OMBUDSMAN PUBLISHES 'SIX LIVES' THE PROVISION OF PUBLIC SERVICES TO PEOPLE WITH LEARNING DISABILITY**

The report demonstrates that more people with learning disabilities have taken up the opportunity of an annual health check to improve their health and enable preventive interventions to stop potential health crises. The report also provides an assessment of the improvements to health care and treatment for people with learning disabilities and family carers.

In addition, the report sets out the priority areas for further development including:

- ➔ Giving greater voice and power to people with learning disabilities and their local communities.
- ➔ Supporting the spread of personal health budgets for people with learning disabilities.
- ➔ Ensuring that Health and Wellbeing Boards have information to support them understand the complex needs of people with behaviour that challenges working with NHS England to make sure the system continues to monitor and improve the health and care outcomes of people with learning disabilities.

**2010 CONFIDENTIAL INQUIRY INTO PREMATURE DEATHS OF PEOPLE WITH LEARNING DISABILITY IN THE SOUTH WEST OF ENGLAND**

The population-based Confidential Inquiry reviewed the deaths of people with intellectual disabilities aged 4 years and older who had been registered with a general practitioner in one of five Primary Care Trust areas of southwest England, who died between June 1, 2010, and May 31, 2012. A network of health, social-care, and voluntary-sector services; community contacts; and statutory agencies notified the Confidential Inquiry of all deaths of people with intellectual disabilities and provided core data. The Office for National Statistics provided data about the coding of individual cause of death certificates. Deaths were described as avoidable (preventable or amenable), according to Office for National Statistics definitions. Contributory factors to deaths were identified and quantified by the case investigator, verified by a local review panel meeting, and agreed by the Confidential Inquiry overview panel. Contributory factors were grouped into four domains: intrinsic to the individual, within the family and environment, care provision, and service provision. The deaths of a comparator group of people without intellectual disabilities but much the same in age, sex, and cause of death and registered at the same general practices as those with intellectual disabilities were also investigated.



The inquiry found that the most common reason for deaths being assessed as premature was: delays or problems with diagnosis or treatment; and problems with identifying needs and providing appropriate care in response to changing needs.

For 29% there was significant difficulty or delay in diagnosis, further investigation or specialist referral, and for 30% there were problems with their treatment. The lack of reasonable adjustments to facilitate healthcare for people with learning disabilities, particularly attendance at clinic appointments and investigations, was a contributory factor in a number of deaths.

In June 2015 NHS England announced the three year national review of premature deaths led by the University of Bristol, the **NATIONAL LEARNING DISABILITY MORTALITY REVIEW (LEDER) PROGRAMME**: A detailed longer-term look at the deaths of people with a learning disability. The programme aims to help reduce premature mortality and healthcare inequalities by conducting, local multidisciplinary reviews of every death in England—and reviewing them nationally. The hope is that lessons learned will influence individual services and simultaneously the national team will pass on the learning nationally. Following recent guidance, every NHS Trust is now subject to particular duties when someone with a learning disability dies, including a full review of recent care.

2016/17 review of the LeDer programme found that in 13% of its reviews into the deaths of people with a learning disability, the persons health had been adversely affected by factors such as delays in treatment, organisational dysfunction and gaps in service provision.

## TRANSFORMING CARE – REDUCING INPATIENT SERVICES

In 2011, the BBC's Panorama programme exposed the abuse of patients at Winterbourne View, an independent Hospital for people with a learning disability and or autism. Further inspections by the CQC of 150 hospitals and care homes for people with a learning disability found inadequate practice in some services, including poor person-centred care, limited appropriate activities and a lack of monitoring and learning from incidents of restraint.

The Department of Health's policy response 'Transforming Care: A National Response to Winterbourne View Hospital' (2012) stated that hospitals were not where people should live and pledged that everyone inappropriately in hospital will move to community-based support quickly, no later than June 2014. Unfortunately this time line was missed.





Winterbourne–Time for Change (2014) found that people with Learning Disabilities were still being placed in long term institutional care rather than supported in the community. The report found that there are still more people being admitted to such institutions than were being discharged – the response was to introduce key recommendations including:

Winterbourne View–Time is Running Out (July 2015) found that the number of people with learning disabilities being discharged from in-patient institutions was now greater than the number being admitted, however the pace of change had been slow.

In 2015 Winterbourne View–2 years on reported on progress against the original report and said that significant recommendations had been achieved, including:

- We know how many people are in inpatient settings and who is responsible for them;
- A more rigorous registration, assessment and inspection approach is in place for learning disability services involving experts by experience;
- The Care Act 2015 underpins and reinforces the importance of good quality, independent advocacy and will play an important part in supporting people, their families and carers to raise concerns when these arise.



**2015 CARE ACT 2014** – A significant change of legislation for Adult Social Care which aims to develop a clearer, more person centred and fairer system. Bringing together legislation into a single statute and makes important changes to the way that care and support works to promote wellbeing and importantly prevent and postpone needs for care and treatment.

The Act is built around promoting independence, choice and control in the community based on people's needs and what they want to achieve in their lives, including treatment, care and support, accommodation, access to the local community, access to work, education and training and overall enablement. The principle of Wellbeing is very important part of the Act and requires providers to look for ways of preventing the need for urgent or crisis support.

Main elements include:

- Choice of provider for care and support.
- Suitability of living accommodation – access to a range of accommodation according to need
- Protection from abuse and neglect.
- Use of direct payments and health personal budgets.
- Right to a Family Life.
- Right to support for family/friends who act as carers.
- Information and advice for service users and families – including signposting.
- Focus on preventing, delaying and reducing the need for care and support.
- Economic and emotional Wellbeing.
- Participation in work, education and training.

The Care Act strengthens the rights of people with learning disabilities and their family carers. It promotes fairer, more personalised care and shifts

the focus of local authorities from providing services for specific groups, to supporting individuals to achieve the outcomes that matter to them.

For the first time in law, family carers have the same rights to assessment and support as the people they care for. The local authority must not make any assumptions about what a family carer is willing or able to do for their relative. The local authority does not have to meet the needs that the carer is willing and able to meet but it is important to make sure that all eligible needs are identified during the assessment to protect against potential breakdown in the caring relationship.

**2016 'THINK AUTISM STRATEGY'** 'Think Autism' sets out clear action the Department of Health and other government departments will be taking to improve the lives of people with autism, primarily through taking actions that will support local authorities, the NHS, other public services and their partners with their local implementation work.

'Think Autism' has a focus on building communities that are more aware of and accessible to the needs of people with autism. It also looks at promoting innovative local ideas, services or projects that can help people in their communities and how advice and information on services can be better joined up.

The Autism Act (2009) places a duty on the Secretary of State for Health and Social Care to publish a strategy for meeting the needs of autistic adults in England, and to review it from time to time. England's first Adult Autism Strategy 'Fulfilling and Rewarding Lives' was published in 2010, with commitment from Ministers across government to transform the support for and experience of autistic people. In April 2014, the Strategy was updated with the publication of 'Think Autism', supported by revised Statutory Guidance in March 2015.



**MENTAL CAPACITY (AMENDMENT) ACT** the Act amends the Mental Capacity Act 2005, which provides a statutory framework for people who lack capacity to make decisions for themselves. The Act is based on the recommendations of the Law Commission report Mental Capacity and Deprivation of Liberty, which was published together with the Law Commission's draft Bill in March 2017.

The Mental Capacity (Amendment) Act would reform the process for authorising arrangements which enable people, who lack capacity to consent, to be deprived of their liberty for the purpose of delivering their care or treatment. This will include people with severe dementia, learning disabilities, head injuries and autistic spectrum disorder. The new legislation means that DoLS are repealed and replaced by a new scheme called the Liberty Protection Safeguards, which aims to streamline the process for approving a deprivation of liberty.

Deprivation of Liberty Safeguards (DoLS) introduced in 2009. Those arrangements have attracted significant criticism for being too complex and bureaucratic. Key court judgments have also widened the interpretation of those who should be recognised as having been deprived of their liberty, with significant implications for local authorities and others involved in administering the DoLS scheme.

**TREAT ME WELL CAMPAIGN-2017 TREAT ME WELL** aims to transform how the NHS **treats** people with a learning disability in hospital. The **campaign** advocates equal access to healthcare for people with a learning disability, and argues that small adjustments can go a long way.

The report found:

- 75% of people with a learning disability said that hospital staff explaining things to them in a way that is easy to understand would improve their experience of going to hospital;
- Two-thirds (66%) of healthcare professionals want more learning disability training;
- 50% of healthcare professionals suggest that a lack of knowledge around learning disability might be contributing to avoidable deaths.





**THE NHS LONG TERM PLAN** (published in January 2019) seeks to improve the health of people living with learning disabilities and/or autism in the following ways:

- ➔ **Improve community-based support** so that people can lead lives of their choosing in homes not hospitals; further reducing our reliance on specialist hospitals, and strengthening our focus on children and young people.
- ➔ To develop a **clearer and more widespread focus on the needs of autistic people and their families**, starting with autistic children with the most complex needs.
- ➔ To make sure that all NHS commissioned services are providing **good quality health, care and treatment** to people with a learning disability and autistic people and their families. NHS staff will be supported to make the changes needed (reasonable adjustments) to make sure people with a learning disability and autistic people get equal access to, experience of and outcomes from care and treatment.
- ➔ To **reduce health inequalities**, improving uptake of annual health checks, reducing over-medication through the 'Stopping The Over-Medication of children and young People' with a learning disability, autism or both (STOMP) and 'Supporting Treatment and Appropriate Medication in Pediatrics' (STAMP) programs and taking action to prevent avoidable deaths through learning from deaths reviews (LeDeR).
- ➔ To continue to **champion the insight and strengths of people with lived experience and their families** in all of our work and become a model employer of people with a learning disability and of autistic people.
- ➔ To make sure that the whole NHS has an **awareness of the needs of people with a learning disability and autistic people**, working together to improve the way it cares, supports, listens to, works with and improves the health and wellbeing of them and their families.



# Essex Demographics

According to Essex County Council's  
*Market Position Statement*  
there are estimated to be

**27,330** people

with a *learning disability*  
living in Essex of which

**5,675** are estimated to  
have a *moderate*  
or *severe* learning  
disability regardless  
of age.

This number is  
estimated to  
increase by

**10%**

over the next decade

to

**6,254**

by 2025.



8,745\*

people in Essex with  
Autistic Spectrum  
Disorders

Due to the advances in care an increasing number of young people with severe and complex disabilities, often accompanied by challenging behaviours, survive into adulthood. Many of these individuals have lifelong need for care and support. Improved healthcare has meant that a significant increase in the number of older people with a learning disability. This figure is also expected to grow at a higher rate of 18% from 819 to 966 people in 2025.

There are estimated to be 8,745 people living in Essex with Autistic Spectrum Disorders. People who have these conditions typically have problems with social interaction and communication. Practical cognitive disabilities and patterns of behaviour which make it difficult to those people to function within the framework of society.

966

predicted number  
of older people  
with learning  
disabilities in 2025





548\*

people in Essex  
have Downs  
Syndrome

52\*

also have  
Dementia

There are estimated 548 people with Downs Syndrome of which 52 also have Dementia. This is a chromosomal disorder associated with major heart malformations, a lesser risk of underdevelopment of the small intestine and a minor but still significant risk of acute leukaemia. 211 adults with learning disabilities living in Essex are estimated to display challenging behaviours, some with physical aggression, the destruction of property, self-harm, fire setting and sexually inappropriate behaviour. Some important facts:

- 1 2 in every 100 people have a **learning disability** and/or **autism**.
- 2 **Annual cost** of bringing up a child with a learning disability and or autism is **three times higher** than bringing up a non-disabled child.
- 3 Children with **special educational needs** are **twice** as likely as other children to be **bullied** regularly.
- 4 **16%** of people with a learning disability **play sport** at least once a week compared with 40% of the general population.
- 5 People with learning disabilities are **20 times** more likely to have **epilepsy** than the general population.
- 6 People with learning disability are **8 times** more likely to have **mental illness**.
- 7 People with learning disability are **5 times** more likely to have **dementia**.
- 8 People with learning disability are **3 times** more likely to suffer from **hypothyroidism**.
- 9 People with learning disability are **twice** as likely to suffer **diabetes, heart failure, chronic kidney disease** or **stroke**.

# Where do we want to be?



**Over the next two years we aspire for individuals who use our services and their families to receive the right support and treatment at the right time:**

- 1** We want to know who are service users with a learning disability and/or autism and identify them in order to make reasonable adjustments at an early stage.
- 2** We want people with learning disabilities and/or autism to live long and healthy lives and have access to personalised health care so that individuals can get the right support and treatment at the right time by understanding and making reasonable adjustments.
- 3** We need to review our training and continuous professional development programme in light of the new consultation document at all levels within the organisation.
- 4** We want to engage with people with learning disabilities and/or autism to inform our training and continuous professional development programme and service improvements.
- 5** We want to raise awareness of the health vulnerabilities of people with learning disabilities and/or autism to avoid premature deaths.
- 6** We want to review the role of the Learning Disability Champion to ensure that there is expertise within the organisation which is sustainable and accessible to support practitioners, service users and families to get the right support and expertise when needed.
- 7** We want to ensure that our staff are aware of, and know how to make reasonable adjustments for people with learning disabilities and/or autism.
- 8** We want to work closely with our partners and contribute to the transition process so that the young people we support can be prepared more effectively for adulthood.
- 9** We will benchmark our services against national and local quality standards and review every 6 months to continually make service improvements.
- 10** We want to ensure that the people with learning disabilities and their families/carers who come into contact with our services are supported to stay as independent as possible.





# Action Plan



## Learning Disability Strategy Action Plan

### RECOMMENDATIONS:

**a** We want to know who our service users are with a learning disability and/or autism and identify them early in order to make reasonable adjustments at an early stage.

**b** We want to ensure that where individuals with learning disabilities and/or autism have capacity to consent they have the choice and control of their support and treatment options and stay as independent as possible. We want to encourage service users to express their views and wishes and always be involved in their support and treatment plans either directly or with the support of family/carer/advocate as appropriate.

### ACTION REQUIRED:

- ➔ As part of the induction process promote the understanding and use of the icon on SystmOne and its effectiveness within the organisation.
  - ➔ Review the customer pathway to identify the earliest point at which reasonable adjustments can be indicated.
  - ➔ Review the reporting systems within the organisation and make recommendations for the improvement of identification, recording and monitoring.
- 
- ➔ Regular communications to operational teams.
  - ➔ Each team to audit and review the number of support and treatment plans developed in partnership with the service user and/or family input and where possible signed by the individual.
  - ➔ Through supervision and mentorship ensure that staff do not discriminate against individuals because of their age, disability, gender, race, religious beliefs, or sexual orientation.
  - ➔ Actively encourage respect, dignity, independence and privacy for both service users and families.

...CONTINUED OVERLEAF >>>

## RECOMMENDATIONS:

...CONTINUED FROM PREVIOUS

b

C We want to review our training and continuous professional development programme in light of the new consultation document 'Learning Disabilities and/or Autism Training for Health Care Staff'. DoH and Social Care published February 2019.

## ACTION REQUIRED:

- ➔ Ensure that service users are listened to and feel able to talk to the staff, if necessary with the support of an interpreter, advocate or family member.
- ➔ Corporately have easily accessible communication aids and systems in place to encourage service users and families to express their views, choices and preferences about the way in which their care is delivered.
- ➔ Encourage service users and families to give feedback about improvements to the service and provide them with accessible tools to do this.

- ➔ The consultation document is extensive and includes suggestions that every employee undertakes further training.
- ➔ Also suggests three tiers:
  - o **Tier 1:** General awareness-This would apply to all staff that occasionally work with individuals with Learning Disabilities and/or Autism – this definition would apply to the whole of the organisation.
  - o **Tier 2:** Largely undefined in the consultation document but would include staff that have 'regular' contact with people who have Learning Disabilities and or autism.
  - o **Tier 3:** Includes staff that are working intensively with people with Learning Disabilities – either directly providing care and support of having or active role in decision making.
- ➔ There needs to be an organisation wide decision around the resources needed to deliver the proposed mandatory training.

...CONTINUED OVERLEAF >>>



## RECOMMENDATIONS:



...CONTINUED FROM PREVIOUS



We want to raise awareness of the health inequalities and vulnerabilities of people with learning disabilities and/or autism to avoid premature deaths.


## ACTION REQUIRED:

**In addition, whilst the outcome of the consultation is unknown there are other steps organisations can take to improve knowledge and skills:**

- 1** Review and refresh of current corporate induction learning disability and or autism awareness session.
- 2** Strengthen governance in relation to adherence to the MCA, so that professionals fully appreciate the requirements of the Act in relation to their own role.
- 3** Identify expertise in partner organisations and how we can learn and share knowledge and skills as a whole system.
- 4** Review and identify current in-house expertise and consider how best to utilise their knowledge and skills.
- 5** Work with safeguarding to develop further the champion role and expertise.

- 
- ➔ Corporate induction should include health vulnerabilities of people with learning disabilities for all clinical staff.
  - ➔ Develop a system for signposting to GP's/primary care where an individual has not received their annual health check.
  - ➔ Training for staff coming into regular contact with people with learning disabilities and or autism to be part of the corporate induction programme and mandatory training where appropriate.
  - ➔ Access to up to date resources: intranet page etc
-


## RECOMMENDATIONS:

-  We want to ensure that our staff are aware of and know how to make reasonable adjustments for people with learning disabilities and/or autism.

Where someone meets the definition of a disabled person in the Equality Act 2010 (the Act), public service providers are required to identify them and make reasonable adjustments to any elements which place a disabled person at a substantial disadvantage compared to non-disabled people. In addition, the Health and Social Care Act 2012 (Section 13G) says that the NHS has a duty to have regard to reducing inequalities in access and outcomes.

## ACTION REQUIRED:

- ➔ Raise awareness of reasonable adjustments and how practitioners can make adjustments to ensure that people with learning disabilities and or autism are not disadvantaged.
- ➔ Develop guidance to support staff when working with people with learning disabilities and or autism.
- ➔ Regular communication within the whole organisation to improve the awareness of how to make reasonable adjustments. **(Appendix 1)**

-  We want to review the role of the Learning Disabilities Champion to ensure that there is expertise within the organisation which is accessible and sustainable to support individuals, families and practitioners to access the right support and expertise when needed.

- ➔ Review and relaunch the role of the Champions and identify learning and development opportunities to ensure they are equipped with the right skills and knowledge and are able to actively disseminate the knowledge to support the wider system, colleagues, families and individuals.
- ➔ We need to develop and promote the role of the Champion from 'practitioners with an interest' to 'practitioners who are experts in this field' **(Appendix 4)**.
- ➔ Consider with our partners opportunities for developing a partnership which has the expertise to work across the system.



## RECOMMENDATIONS:

**g** We want to work closely with our partners and contribute to a smooth transition for young adults with learning disability and/or autism so that the people we support can be prepared more effectively for transition into adult services.

## ACTION REQUIRED:

- Co-operate and communicate with other providers of the individuals care and support where this responsibility is shared or when the individual is transferred to one or more services.
- Support individuals to know where to access other community, health and social care services as required.
- Have good communications skills and a firm understanding of each provider's responsibilities making sure all support staff are aware of this so the support from either provider doesn't break down.
- Develop a resource directory so that staff know where to access advice and support system wide **(Appendix 2)**.
- Enlist the support of the Learning Disability Champions to navigate the transitions process.
- Keep up to date on what resources are available for people moving between services – either through an electronic or paper resource directory **(Appendix 2)**.

**h** We will encourage our service users with learning disabilities and/or autism to stay as healthy as possible and make healthy nutritional choices.

- In our wards and supported living environments we will support individuals to make healthy choices recognising individual preferences, cultural and dietary requirements.
- Support individuals to access specialist dietary support and advice where required.

We will benchmark our services against national and local quality standards and review this every 6 months to continually make improvements.

- Ensure that staff have up to date food hygiene training.
- Develop a system for monitoring the use of reasonable adjustments within the organisation **(Appendix 3)**.
- Monitor fair access to investigations, treatment and support for individuals.

## RECOMMENDATIONS:

- Service users are protected from abuse or the risk of abuse and their human rights are respected and upheld.

## ACTION REQUIRED:

- ➔ In line with Provide policy we will act to identify and prevent abuse from happening in the service and respond immediately and appropriately when it is suspected that abuse has occurred or is at risk of occurring in line with the Safeguarding policies.
- ➔ Ensure that the appropriate learning disability and or autism guidance, training and support is available to staff, put into practice and implemented and all policies are read and adhered to.
- ➔ We will monitor the use of the Mental Capacity Act 2005 when it is in the best interest of the patient.
- ➔ Where appropriate use of the Deprivation of Liberty (DoL) process to ensure that individual is safe and in compliance with the legislation.
- ➔ Ensure that individual concerns are believed, investigated and supported following any alleged abuse.
- ➔ Ensure that individuals, families and carers are informed about how to identify and report abuse as well as sources of support outside the service.
- ➔ Actively encourage service users and families to raise issues and concerns when necessary and give them the opportunity and tools to do so if they have any form of communication difficulties.



## RECOMMENDATIONS:

**j** Promoting effective communication is at the heart of reducing premature mortality.

All organisations which provide NHS care and those providing publicly-funded adult social care are legally required to follow the Accessible Information Standard. The Standard requires a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.

## ACTION REQUIRED:

- ➔ Work closely with carers, our partners, social care and the voluntary sector to ensure there is a holistic approach to the support, care and treatment of people with a learning disability and or autism.
- ➔ Raise awareness of health vulnerabilities for people with learning disabilities and/or autism.
- ➔ Where appropriate identify whether or not the individual has received their annual health check and if not refer them back to Primary Care.
- ➔ Have a robust process in place to prevent, investigate and monitor premature deaths of people with a learning disability and/or autism receiving care, treatment and support.

**k** Develop a Communication Strategy to:

Raise awareness of the learning disability and or autism indicator on SystemOne.

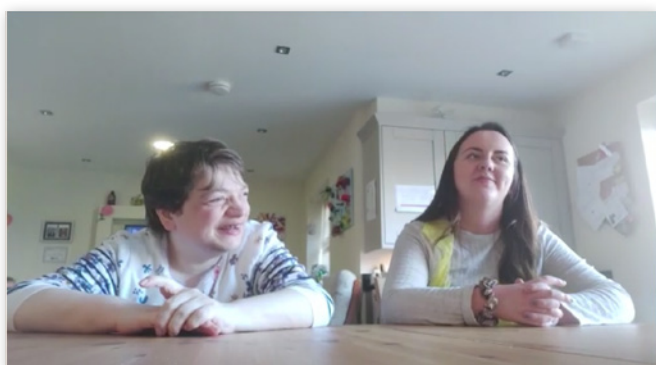
Review the information that is provided to people with learning disabilities and or autism about appointments, assessment, treatment, procedures and complaints to ensure that it's in easy read format and comprehensible.

- ➔ Roll out the strategy within the organisation
- ➔ Team Brief
- ➔ Induction
- ➔ Develop easy read information
- ➔ Use of interpreters



# Our Stories

We wanted to our service users to be involved in the development of this strategy and in order to do so our team conducted interviews with some of the residents at our supported living accommodations. We asked them about their experiences, specifically focusing on points made in section 2. Feel free to watch the full videos here to find out what our residents told us.



Nicola



Sammy



Liam



Kurtis



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# Learning Disability and/or Autism Initiative 2021

Working differently and more effectively to improve the lives of individuals who have a learning disability, and/or autism.

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