NHS Sunderland CCG Learning Disabilities & Autism Primary Care Programme

Information Document

Better health for Sunderland

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1) Introduction

The Learning Disability and Autism Primary Care Programme consists of a combination of this information / guidance document for Primary Care to use as a resource / point of reference and the bespoke training which will be delivered at the TITO events in May, June & July 2017 for clinical and non-clinical staff.

There has been a lot of work put into the development of this programme, a very big thank you is due to all the following individuals who willingly gave their time to work collaboratively together to ensure the programme was established and rolled out. Those individuals are:

- Alex Harrison – HCA, East Locality;
- Angela Lockyear – Clinical Lead & General Practice Nurse, North Locality;
- Ann Fox – Director of Nursing, Quality & Safety, Sunderland CCG;
- Ashley Murphy – Primary Care Facilitator, NTW;
- Carole Rutherford – Director of AIM;
- Carol Wilkinson – Joint Commissioning Team Secretary, Sunderland CCG;
- Chrissie Todd – West Locality Practice Manager & Practice Manager;
- Dr Ian Pattison – Chair of Sunderland CCG & GP, East Locality;
- Dr Jackie Gillespie – Executive GP, Medicines Optimisation Clinical Lead & GP, West Locality;
- Emma Middleton – Receptionist, Coalfields Locality;
- Gloria Middleton – Business Manager, Coalfields Locality;
- Helen Brace – East Locality Practice Nurse & Practice Nurse, East Locality;
- Jackie Russell – Washington Locality Practice Manager & Practice Manager;
- Kay Clark – Practice Manager, Washington Locality;
- Leslie Blakeston - West Locality Practice Manager & Practice Manager;
- Linda Reiling – Joint Commissioning Manager for Mental Health / Learning Disabilities / Autism and Dementia Lead, Sunderland CCG;
- Lisa Clark – Managing Director of Sunderland People First;
- Wendy Page – North Practice Manager, North Locality.

A big thank you to the focus groups who were actively involved in the coproduction of this document, Washington Community Resource Centre Patient Forum and the Autism In Mind Advocate Group both gave their time and experience to help support and develop this work.

There are key individuals from general practice who have committed their times and are dedicated to improving everything and anything to ensure that our community of learning disability and autistic individuals are able to access primary care and receive the medical treatment they deserve in the right place at the right time.

2) Background

Vision statement from "service model": "Children, young people and adults with a learning disability and / or autism who display behaviour that challenges, including those with a mental health condition, have the right to the same opportunities as anyone else to live satisfying and valued lives and, to be treated with the same dignity and respect. They should have a home within their community, be able to develop and maintain relationships and get the support they need to live a healthy, safe and fulfilling life."

- *"The success in this lies not within systems and processes but within human connections, commitments, accountability and sustainable relationships that are non-adversarial"* **Commissioner**

Following the Government's response to the abuse uncovered by the Panorama TV programme of 31st May 2011 and 29th October 2012.

"Transforming Care: A national response to Winterbourne View Hospital" (Dec 2012) was published; this included specific actions for National Health Service England (NHS England), Clinical Commissioning Groups (CCGs), Local Authorities (LA), Commissioners who buy health and social care and General Practice.

Following guidance from "DH Winterbourne View Review – Concordat: Programme of Action" December 2012 Sunderland developed a "concordat list" which identified individuals who were receiving treatment in specialist Hospitals. Local oversight and scrutiny measures were developed including individuals who had a learning disability, their families or support as well as representatives from LA and NHS. In the intervening years National progress was closely scrutinised by Government and three national reports were published:

- **Time for Change: Bubb Report Nov 14;**
- **Transforming Care Two Years on: Jan 15;**
- **Transforming Care – Next Steps: Jan 15.**

The LeDeR programme: The Learning Disabilities Mortality Review (LeDeR) Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. It aims to guide improvements in the quality of health and social care service delivery for people with learning disabilities and to help reduce premature mortality and health inequalities faced by people with learning disabilities.

A key part of the LeDeR Programme is to support local areas to review the deaths of people with learning disabilities. The programme is developing and rolling out a review process for the deaths of people with learning disabilities, helping to promote and implement the new review process, and providing support to local areas to take forward the lessons learned in the reviews in order to make improvements to service provision.

There is a lot of pressure placed on primary care, they are viewed as the access point for all healthcare. Primary Care has many responsibilities; they work between competing agendas, priorities and regulations. We recognise and acknowledge that it must be incredibly difficult and frustrating for General Practices to navigate their way through all these guidance documents and work out the expectations they need to fulfil and how to align these to the primary care workload.

This programme was developed to assist primary care to help them navigate their way through all of these regulations and documents and to clearly outline a plan for the future.

3) Health Needs

People with learning disabilities and autism are a very diverse population with differing needs and are one of the most vulnerable groups in society, experiencing health inequalities, social exclusion and stigmatisation. Amongst those with more severe learning disabilities, there have been considerable life changes for many, with the closure of learning disability hospitals. Following the enquiry and reports after the closure of Winterbourne View Hospital (DH, 2012) and the development of the government's 'Valuing People Now' strategy (DH 2009), there are now clear guidelines in place covering all aspects of the health needs of people with learning disabilities. Under the Disability and Equality Act (2010), 'reasonable adjustments' are required in all practices and within their procedures to ensure that discrimination against people with learning disabilities does not occur.

People with learning disabilities face a number of challenges in using health services. These include understanding literature they have been given, keeping appointments and following treatment regimes. It is important that people who provide healthcare can identify when a person has a learning disability or autism so they can make 'reasonable adjustments' to their care. People with learning disabilities tend to be less physically active and a higher proportion of them are obese compared to the general population. Local information on this is very limited but it does seem to show this is the case.

As well as lifestyles, another major reason for this poor health experience is poorer access to health promotion and early treatment. The health checks that are available either help to prevent people from developing illnesses or treat them early to make it easier and more likely to recover. Local data was only available from a few areas. It shows a similar pattern to national research including:

- High rates of people with learning disabilities and / or autism refuse or do not attend cancer screening appointments;
- Less than half of people with learning disabilities and / or autism who have diabetes get an annual review to help manage their condition in the best way possible;
- Advice on sex, relationships and help with contraception is poor.

Life expectancy of those with learning disabilities and / or autism is shorter than the general population, though this has increased recently. In addition a number of national reports have highlighted that adults often experience barriers to accessing healthcare services, poor levels of care and they are more likely to die from a preventable cause than the general population.

Disability & Equality Act 2010 and Reasonable Adjustments: Since the Disability & Equality Act 2010, disabled people have important rights of access to everyday services. Service providers are now obliged to make reasonable adjustments to premises or to the way they provide services. Access to services is not only about physical access, it is about making services easier to use for everybody, for example longer appointment times and more accessible health promotion information.

4) Plan for Primary Care

Our Vision – The vision for the future is to establish a Primary Care Steering Group into Sunderland's transforming care structure. The steering group will be the link between the Local Implementation Group and the practices across Sunderland relating to the Transforming Care Agenda.

The plan is to have one overarching plan which outlines how across the whole of Sunderland we are going planning on delivering all the expectations and requirements within transforming care while ensuring primary care remain empowered and leaders in their own areas.

There has been a primary care action plan drafted by the steering group and over the next year they will finalise that plan and start delivering specific actions which will support practices across Sunderland, the plan which is being pulled together by primary care staff who sit on the steering group will clearly outline what the focus areas they believe should be prioritised over the next 3 to 5 years. Once the plans have been agreed and are being delivered it will be the role of the Chair of the Primary Care Steering Group to regularly attend and update the LIG on progress made. The Local Implementation Group (LIG) has a wider Sunderland action plan and progress made on that is regularly reported to the North East & Cumbria Transforming Care Board, Sunderland CCG Quality, Safety & Risk Committee and Sunderland CCG Mental Health Programme Board.

What is a Learning Disability?

Mencaps definition: Mencap (2016) define a learning disability as a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life.

People with a learning disability tend to take longer, or may never learn and some 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 fulltime care and support with every aspect of their life – they may also have physical disabilities.

People with certain specific conditions can have a learning disability too. For example, people with Down's syndrome and some people with autism have a learning disability. It's important to remember that with the right support, many people with a learning disability in the UK can lead fulfilling lives.

A learning disability affects the way a person learns new things in any area of life, not just at school. A learning disability affects the way a person understands information and how they communicate. Around 1.5m people in the UK have one. This means they can have difficulty:

- understanding new or complex information;
- learning new skills coping independently.

It is thought that up to 350,000 people have severe learning disabilities. This figure is increasing.

A learning disability can be mild, moderate or severe. Some people with a mild learning disability can talk easily and look after themselves, but take a bit longer than usual to learn new skills. Others may not be able to communicate at all and have more than one disability (see Profound and multiple learning disability section below).

Some children with learning disabilities grow up to be quite independent, while others need help with everyday tasks, such as washing or getting dressed, for their whole lives. It depends on their abilities.

Profound and multiple Learning Disabilities

A diagnosis of a profound and multiple learning disability (PMLD) is used when a child has more than one disability, with the most significant being a learning disability.

Many children diagnosed with Profound and Multiple Learning Disabilities will also have a sensory or physical disability, complex health needs, or mental health difficulties. People with Profound and Multiple Learning Disabilities need a carer or carers to help them with most areas of everyday life, such as eating, washing and going to the toilet. (NHS Choices).

What is it like for someone with a Learning Disability to come into practice?

Going to the doctors can be a very stressful experience for a person with a learning disability.

No doctor intends to discriminate against his or her patient, but the evidence shows that people with learning disabilities have poorer health outcomes than that of the general population. Sometimes people with a learning disability experience diagnostic overshadowing.

Diagnostic overshadowing has been defined as follows:

- *diagnostic overshadowing (Concept) - once a diagnosis is made of a major condition there is a tendency to attribute all other problems to that diagnosis, thereby leaving other co-existing conditions undiagnosed.*

It is extremely important that the health professional takes a full history of presenting complaints from the patient with a learning disability and/or their carer to ensure all physical causes of illness or altered presentation have been investigated and excluded.

It is not acceptable to assume someone ‘behaves’ the way they do and attribute it directly to the learning disability or autism. This is often not the case and an underlying reason for agitation could be extreme pain caused by toothache for example.

People with learning disabilities also report that the health professional sometimes does not address them directly and will steer the questions to the carer that is present without attempting to understand the individual’s ability to communicate and explain.

It can be very difficult for people with a learning disability to understand what is expected from them at a routine health appointment. They do not always know what certain equipment is for or why general practice want to carry out tests and investigations. This is why a full explanation is always required and the use of photographs, drawings and other objects of reference are useful. This would be an expected reasonable adjustment, just as one would provide information to someone who did not speak English in a language they understand.

What is a learning difficulty and how does it differ?

Learning Difficulty is often confused with the term learning disability. An example of this is with dyslexia and mental health problems. Mencap describes dyslexia as a learning difficulty because, unlike learning disability, it does not affect intellect.

The difference between a learning difficulty & a Learning Disability?

Distinguishing between learning difficulties and learning disabilities is quite a complex issue.

As described above, a learning difficulty does not affect general intelligence, whereas a learning disability is linked to an overall cognitive impairment.

Some examples of specific learning difficulties are:

- Dyspraxia;
- Dyslexia;
- Attention Deficit Hyperactivity Disorder (ADHD).

Below are some of the estimated numbers of people affected by some of the most common learning difficulties:

- Approximately 10% of the population are affected by dyslexia to some extent;
- Dyspraxia affects between 5 and 10% of the population to some extent, with around 2% being affected severely;
- Attention deficit hyperactivity disorder (ADHD) affects approximately 3–9% of school-aged children and young people, with around 1% being affected severely. (Foundation for people with a learning disability).

The distinction between disabilities and difficulties continues to be a subject for debate and although they are often interchangeable, it is broadly accepted that there is a difference between learning disabilities and learning difficulties as follows:

- **Learning disability** – is a general term that refers to individuals who find it harder to learn, understand and communicate. Other terms that are used to describe an individual’s situation include complex needs;

- **Learning difficulty** – is often used in educational settings and refers to individuals who have specific problems with learning as a result of either medical, emotional or language problems. Children and young people requiring special education needs (SEN) are often described as having a learning difficulty.

What is Autism?

Quotes from a Focus Group – Autism in Mind (AIM) in Sunderland:

Autism is a lifelong developmental condition that affects and impairs communication skills and how individuals relate to other people. These conditions are commonly described as difficulties with:

- Social communication and interaction;
- Restrictive, repetitive patterns of behaviour, interests or activities;
- People with autism may also experience some form of sensory over-sensitivity or under-sensitivity to the environment around them. For example to sounds, touch, tastes, smells, light or colours.

Autism is often described as a 'spectrum' because the condition affects people in many different ways and to varying degrees. This means that, while all people with autism share certain difficulties, being autistic will affect them individually. Some people with autism also have learning disabilities and some will exhibit behaviour that many describe as challenging. As a result, people need different levels of support.

Asperger syndrome is a form of autism (although no longer diagnosed in its own right) and is a lifelong disability that affects how a person makes sense of the world, processes information and relates to other people.

People with Asperger Syndrome are of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language.

> *“A person can be high functioning (verbal, good academic skills, fair to good personal care), but have moderate to severe autism (rigid inflexible thinking, strong sensory issues, poor emotional regulation, delayed processing, and impaired ability to relate with others). Also, a person can be considered low functioning (poor verbal skills, limited academic skills, and minimal personal care skills) but only have mild autism (more flexibility, calmer emotionally, less sensory sensitivities, and more socially connected).”* ***(Bill Nason, 2012)***

People with autism will have days when they function well. They will also have days when they do not function well. Verbal ability does not reflect a higher level of functioning. An inability to use language does not reflect a lower level of functioning.

Autism will affect how the individual relates to people, how they communicate and how they make sense of the environment around them

If someone with autism is functioning well it means that they are in the right environment for them and that they have the right level of support for them. If you change the environment or the level of support the likelihood is that the way in which that person is functioning will change rapidly.

Autism is not rare and is much more common than most people think. There are around 700,000 people in the UK living with autism – that's more than 1 in 100 people (National Autistic Society)

Autism and suicide / suicidal thoughts

Recent findings highlight a staggering rate of suicidal thoughts among adults with Asperger's syndrome.

Depression is an important potential risk factor for suicidal thoughts in people with this Asperger Syndrome/Autism. Dr. Simon Baron-Cohen, Dr. Sarah Cassidy, Director and Researcher at the Autism Research Centre (ARC) at the University of Cambridge, U.K.

The research team states in the journal *Lancet Psychiatry* that Asperger's syndrome in adulthood is often linked to depression. Survey data was used on 256 men and 118 women who were diagnosed by a clinician with Asperger's syndrome between 2004 and 2013 in England.

Any depression, suicidal thoughts, or plans were recorded on a self-report questionnaire, along with self-reported autistic traits and empathy.

Two-thirds (66 percent) of the respondents reported suicidal thoughts, 35 percent reported plans or attempts at suicide, and 31 percent reported depression.

Compared with the general population, adults with Asperger's syndrome were nearly 10 times more likely to report suicidal thoughts. They were also significantly more likely to have these thoughts than people with one, two, or more medical illnesses, or people with a psychotic illness.

Those with Asperger's syndrome and depression were four times more likely to report suicidal thoughts and suicide plans or attempts than those with Asperger's syndrome but without depression. Having a higher level of self-reported autistic traits was also linked to a greater risk.

Self-injurious behaviour - National Autistic Behaviour

Self-injury can be one of the most distressing and difficult behaviours that parents, carers, family members and people with autism themselves may face.

Sometimes referred to as self-harm, self-injurious behaviour is any activity in which a person inflicts harm or injury on themselves. About half of people with autism engage self-injurious behaviour at some point in their life. It can take many different forms, including:

- head banging (on floors, walls or other surfaces);
- hand or arm biting;
- hair pulling;
- eye gouging;

- face or head slapping;
- skin picking, scratching or pinching;
- forceful head shaking.

People across the spectrum and of all ages may engage in self-injurious behaviours at some point. People who engaged in self-injurious behaviours as children may return to these as adults during times of stress, illness or change.

Usual behavioural intervention approaches are not always appropriate. Seek professional guidance for any self-injurious behaviour which is difficult to manage or resistant to intervention, or for any behaviour which places the person at risk of harm.

Mental Health and Autism – National Autistic Society

Autism is not a mental health condition but mental health issues can be more common for people with autism than in the general population, the mental health of people on the spectrum is often overlooked.

Anxiety disorders are very common amongst people with autism. Roughly 40% have symptoms of at least one anxiety disorder at any time, compared with up to 15% in the general population. Understandably, this can lead to sadness or depression – one reason why a mixture of anxiety and depression is common.

It is thought that a combination of factors, leading to vulnerability to stress, is likely to explain why anxiety disorders are so common in people with autism. Biological differences in brain structure and function, a history of social difficulties (leading to decreased self-esteem and a tendency to think of threats as greater than they are) and problems with finding flexible responses to apparent threats are all likely to contribute.

Many people on the autism spectrum may have difficulty describing the symptoms they experience. A sudden change in behaviour could mean they have developed an anxiety disorder, even if there is no complaint of the typical symptoms.

Here in Sunderland, autism is referenced in the joint strategic needs assessment (JSNA) which highlighted that the average prevalence of children and young people with a special educational need where the primary need is autistic spectrum conditions is 1.7% compared to the expected prevalence of 1.2%.

The above average prevalence means that education, health and social care services need to work closely together to provide timely support to the increasing numbers of people living with autism in Sunderland.

Even highly verbal individuals with autism would also benefit from information being presented to them in an easy version, or at least being offered the opportunity to have the information in an easy read format. Having information in an easy read format will enable them to process information, when they are feeling anxious or stressed. Verbal ability and the ability to communicate effectively is the first thing to be affected, when someone with autism is experiencing high levels of anxiety. Many people with autism think in pictures, regardless of their verbal ability, and so an easy read version would aid them to process important information.

Autistic individuals experience the world through their senses which impacts on how they behave, react and engage with the outside world, this in fact can often cause the main issues when trying to access appropriate healthcare. Some problem areas they encounter can be due to:

- Sensory processing;
- Touch (tactile system) If an individual is hypo-sensitive to touch they may have a high threshold to pain or temperature and not mind heavier pressure when touched. This could cause difficulty when being examined by the doctor as the person with autism may not appear to be in pain but could, for example, have broken a bone. They may be unable to decode the different body sensations to recognise it as pain.

They can display unusual responses to pain such as laughing, humming or stripping which may make it difficult for the doctor to recognise and identify the problem. It may be that change in behaviour is the only indicator that a person with an ASD is in pain.

On the other hand, a person with an ASD may be hyper-sensitive to touch. They may experience the slightest touch as uncomfortable or even painful. They will therefore withdraw from touch which can cause difficulties when a doctor is trying to conduct a physical examination. Materials used could also be a problem, for instance the paper sheet on the examination table; cotton wool or plasters may cause particular discomfort.

Noise

Some doctor's surgeries use buzzers to indicate when it is a patient's turn to see the doctor. They may also have music playing in a waiting room. Crying babies or children in the waiting room may also be quite noisy. For those with hyper-sensitive hearing, these types of noises can be magnified and become quite disturbing. Also with this heightened volume, surrounding sounds could become distorted. For the person with an ASD, this could cause difficulty in recognising sounds, such as a name being called for instance.

Personal space and body awareness

A crowded waiting room may be quite distressing for someone with an ASD who may need their personal space. Similarly close proximity to the doctor could be quite uncomfortable for the patient.

Problems can also occur when trying to explain where pain is experienced. Those who have difficulty with body awareness may not be able to experience where different body parts are.

What is it like for someone with Autism to come into practice?

It can be a problem for patients with autism to indicate where pain is, due to communication difficulties. It may also be difficult for them to understand what a doctor is asking or to understand when the doctor is explaining what they are going to do to them

The build-up of going to see a healthcare professional begins with the thought/realisation that the person with autism needs medical advice or help. It can take several days, weeks or even months before the individual tries to initiate contact and make an appointment to see their GP or healthcare professional.

Having to make a telephone appointment can be extremely stressful for someone with autism. Speaking to someone they do not know well, but who they have to explain to, why they need to see a doctor can be so difficult for them that some individuals hang up because they are being asked too many questions.

Not knowing what questions they are going to be asked when they get through to their practice, is one of the things that worry individuals with autism the most. The people who answer the phones are busy people and they expect the patient at the other end of the phone to answer their questions directly and quickly. Someone with autism might have spent hours preparing what they wanted to tell the person who answers the phone to them. All of that is then lost when the person they speak to refers throughout to their own prepared script. This can create a great deal of anxiety for the person with autism.

The journey is made even worse for the autistic patient if they are then told that the doctor on call will have to ring them back to see if they really need an appointment. This means that the autistic adult has to deal with the stress and anxiety of having to speak to someone else that they do not know well. It also makes them question if they really do need to see a doctor; even if the doctor ringing them back is just standard practice.

When eventually the person is given an appointment the appointment is always for a specific time. This is a very important issue for people who have autism. If the appointment is for 11am and they are still waiting to see their GP at 11.30am, their levels of anxiety will rise. The longer they have to wait for their appointment the greater the chance that they will be unable to communicate effectively with their doctor when they do go in to see them. Even if the individual has visited their practice previously it will not necessarily stop the anxiety that they will feel every time they enter the practice.

Doctor’s surgeries tend to be full of people who are ill, or at least are there because they need to see a doctor; these are two things that individuals with autism don’t cope well with. Even though the person waiting to see the doctor is there because they are themselves ill, the prospect of having to sit with other people who are ill, from whom they may catch something in addition to what they are waiting to see their GP for is very stressful for them.

Having to stand in a queue of other people to check in can be traumatic for someone with autism. They are aware of the close proximately of the people standing in the queue, and even with the notices displayed in some surgeries, asking patients not to stand too close to other patients while someone is speaking to the receptionist, the distance between the person with autism and the next person in the queue is not big enough for them to feel comfortable.

Add to that the fact that if there ‘is’ a notice the autistic adult will then start to hyper focus on the distance between the patients that are standing next to them in the queue, and ask themselves if they are giving the people standing next to them enough room.

While checking in via an automated system might be better for some people with autism, for many it simply adds to the overload they are already feeling and challenges their ability to correctly process the questions that the screen presents to them.

From the moment someone with autism walks into their GP practice their senses are overloaded, crowded and busy waiting rooms present individuals with autism with a sensory nightmare. The sensory experience of a GP practice can be unbearable for someone who has autism and the anxiety induced insufferable.

Although patients are given an appointment time GPs can and do run late. Although this is unavoidable it creates uncertainty and escalates the anxiety that an individual with autism is already experiencing.

Not knowing how long they are likely to have to wait for their appointment, and not knowing what will happen when they finally get to see their GP, are only some of the uncertainties that individuals with autism have to face every time they need to see their GP or healthcare professional.

The multitudes of uncertainties that someone with autism faces each time they go to see their GP begins before their visit:

- Will my appointment be on time/late?
- Will I have to sit next to someone who wants to talk to me?
- Will I have to sit next to someone who is coughing?
- Which seat should I sit in?
- Will I see the doctor I am expecting to see?
- Will the doctor ask me a lot of questions?
- Will I understand their questions and be able to answer them?
- Will they want to examine me?
- Will I need to have a blood test?
- Will I need to have my blood pressure taken?

Although everyone will probably ask themselves all of the above when they go to see their doctor, it probably won’t affect their ability to communicate effectively with their GP when they see him.

What appears to someone with autism to be a never ending list of uncertainties, and not knowing what to expect when they do see their GP, can have a huge impact on their ability to communicate effectively when they do see their GP.

Useful information for practices to read and review is:

- Autism Strategy (**Appendix 1**);
- Think Autism (**Appendix 2**).

What are the similarities of Learning Disabilities & Autism?

Similar issues experienced by both people who have a learning disability and those who have autism are as follows:

- Impaired communication skills;
- Increased anxiety;
- Behaviour that appears to be challenging;
- Have increased health needs;
- Risk of premature mortality, due to co-morbidities and unmet health needs;
- Advocacy of some form to navigate and negotiate;
- Difficulty in access to services.

What are the differences of Learning Disabilities & Autism?

- People with a learning disability may easily be recognised by appearance where autism is often a hidden disability;
- People with a learning disability typically have better access to specialist services than those with autism;
- People with autism will have multiple sensory processing difficulties;
- IQ and verbal ability in autism does not diminish the impact of the autism;
- People with autism may appear more articulate, may ask more questions.

Co-morbidities of Autism

Understanding the common comorbidities that coexist with autism? Autism is rarely a standalone condition and there are some conditions that commonly coexist with autism.

It would be helpful for individuals with autism if their GP and healthcare professionals knew what the most common comorbidities that coexist with autism are:

- **Epilepsy** – It is estimated that as many of one third of individuals with autism will also have epilepsy;
- **Gastrointestinal Disorders** – are among the most common medical conditions associated with autism. These issues range from chronic constipation or diarrhoea to irritable and inflammatory bowel conditions. They can affect persons of any age. But in the context of autism, they have been most studied in children**;**
- **Eating Disorders** - are very common in people with autism and can be very complex. Eating disorders can stem from sensory issues with food. Individuals with autism often have a restricted diet because of their sensory issues. Internal sensory issues (interoception) can impact in such a way that a hypo sensitivity will mean that the individual will not know when they are full and will eat far too much. While hypersensitivity will mean that they will not know when they are hungry and so will have no desire to eat. Many individuals with autism have serious weight problems because of their interoception sensory issues that often present as eating disorders;
- **Hypermobility** – Joint hypermobility and low muscle tone affect stability and muscle strength. Toe walking can be an indicator that someone with autism may have joint hypermobility and low muscle tone. Individuals with autism often have difficulties with posture, coordination and motor planning. Recent studies show that movement difficulties are very common in children on the autistic spectrum, and importantly, poor motor skills;
- **OCD** – Individuals with autism often display obsessive and compulsive behaviour but this is not the same as someone who has a diagnosis of OCD which is an anxiety disorder. OCD is one of the most common comorbidities for someone who has a diagnosis of autism**;**
- **ADHD -** ADHD is common in people with autism. If someone has ADHD, they have significant difficulties with things like poor attention, over-activity and impulsiveness;
- **Sleep Disorders –** Sleep disorders are very common and are reportedly as high as 80% in children and adults with autism.

Pain Thresholds in people with Autism?

Individuals with autism can have unusual reactions to sensory stimulation - either no reaction at all or an over-sensitive reaction. This also applies to pain threshold. It is important to note that some individuals might have a very high tolerance for pain or conversely a very low threshold for pain.

Comorbidities for people with learning disabilities?

People with learning disabilities have a shorter life expectancy and increased risk of early death when compared to the general population. Life expectancy is increasing, in particular for people with Down’s syndrome, with some evidence to suggest that for people with mild learning disabilities it may be approaching that of the general population. All-cause mortality rates among people with moderate to severe learning disabilities are three times higher than in the general population, with mortality being particularly high for young adults, women and people with Down’s syndrome.(IHAL, 2010)

The Department of Health have continuously emphasised that Primary, Acute and Specialist NHS Trusts must play in a central role in meeting the health needs of people with learning disabilities as often people with a learning disability unfortunately often have many comorbidities.

Please see **Appendix 3** for a detailed report by IHAL (Improving health and lives) for more detail in regards to this.

Pain Thresholds in people with Learning Disabilities?

There is a need to challenge common assumptions that people with a learning disability have higher thresholds of pain and/or the potentially dangerous suppositions of exaggerating or faking pain. The challenge lies with the healthcare professional been able to easily identify the pain in a person where there is no verbal communication or outward displays of pain or discomfort.

It can be helped if care givers are asked to keep records of distress or possible indications of pain to establish if there are any links to when the pain occurs is it intermittent, acute or chronic perhaps?

An excellent document that can be used is called the DISDAT tool. This is an assessment that should be carried out by someone who knows the person very well and works on the premise that the person is well and free of pain and discomfort, therefore been able to provide a pen picture of what pain free looks like. This might be the person makes happy noises, smiles, is active, then a repeat assessment can be carried out that measures the changes in people thus providing clues that's the person has pain or distress.

Handy Tips

- Please click on the link to access website for more information about Disdat tools. The Health Promotion Team in Sunderland could assist in the completion of this useful assessment if a referral is made.

DISDAT TOOL - http://www.stoswaldsuk.org/how-we-help/we-educate/resources/disdat/disdat-tools.aspx

Primary Care Audits (Regional & Local)

In May 2016 the North East and Cumbria Learning disability Network asked the GAPS (General Access to Primary Services) to facilitate an audit which would begin to measure the quality of annual health checks across the region. This was done by carrying out a questionnaire for 10% of all annual health checks provided across Sunderland therefore a total of 61 checks were audited.

As a result of this, an annual health checks action plan for improvement has been developed see **Appendix 4.**

A NHS England Template for delivering annual health checks is currently under development and should be available in the spring of 2017.

Once this becomes available it will be beneficial to all practices to use it as it will offer a standardised approach to what should be included within the annual health check which will standardise the check and ensure equity of care for people with a learning disability. This is also part of the action plan for improving the quality of annual health checks for people with a learning disability across Sunderland. Once it becomes available it will be circulated to all practices to use.

For more information about carrying out an Annual Health Check, see Dr Matt Hoghton's document: A step by step guide for GP practices: annual health checks for people with a learning disability.

5) Reasonable Adjustments

It is important that when a person enters the surgery they feel safe. It’s important for primary care staff to be aware that not all disabilities can be seen.

Staff need to be aware if their patients who are coming into the surgery that day and if there are any reasonable adjustments which may need to be in place for when they come in for their appointment. This could be anything from ensuring a quiet room is ready to the patient can sit if they need to be somewhere quiet, it could be that staff need to watch out for that person’s name to come up so they can let them know it’s their turn for the appointment or helping them to the correct room for their appointment.

A person centred approach is important as it allows the patient to have a say in how they would like their needs met.

When a person with learning disabilities comes to reception it’s important that staff communicate with the person (not just the carer if they come with one), greet them like any other person no matter how they communicate and ask how you can help them.

The visit should be accessible as possible which in turn will make it as much as a positive experience as possible. Staff should speak clearly and have patience (especially important during telephone discussions) if the individual has poor speech / understanding, processing or hearing. If you know the person needs extra help, make sure that you inform everyone involved in that individuals care.

What is a reasonable adjustment for a person with a Learning Disability?

People with a learning disability experience health inequality, experience a wider range of health problems than the general population and may be socially excluded.

People with a learning disability have a right to access health services and these should be provided within the current legislative framework and in a way which upholds the principles of inclusion and respect, and conforms to professional standards.

Access to health care may rely on mastery of modern communications in order to book appointments. Barriers to appropriate and timely access to health services operate both outside and within health services. The law says that all health services must think about people with disabilities. They have to ask “What extra things do we need to do, so people with learning disabilities can get health services as good as other people?”

This may be:

- Making sure that information on health services is accessible to people with learning disabilities;
- Nurses with special skills to look out for people;
- Giving people more time with doctors and nurses;
- Making sure that annual health checks happen for everyone and that any health problems are treated.

Aiming for equality doesn't necessarily mean treating everyone the same. For people with learning disabilities to achieve the same health outcomes as the rest of the population, doctors may sometimes need to put more effort in, allow more time or do things differently.

By making a reasonable adjustment to your practice, like allowing more time for your first appointment with a patient who has a learning disability, you'll be fulfilling not only an ethical requirement, but a legal one too.

How to make a reasonable adjustment?

In order to deliver dignified, respectful and compassionate care you will need to take extra time.

Arranging the appointment to see you as a doctor may have required considerable effort for the person with a learning disability and their carers. Try to offer double the usual appointment, outpatient time or consulting time and be mindful that many carers will have other commitments. People with learning disabilities say that negative or unhelpful attitudes of health care workers deter or stop them from seeking help.

Communicate with the person with a learning disability first and involve them as much as possible.

People with learning disabilities need to be encouraged and empowered to speak for themselves. Try and work out how much understanding someone has at your first meeting, and talk to them in a way that they can understand.

When you meet a person with learning disabilities who is unable to communicate, ask the supporter if they have any special ways in which they communicate. Use these special ways if you can.

Also if there are relevant pictures that the person would recognise, use them. People with a learning disability are more likely than the rest of the population to have communications impairment and therefore would require special consideration.

Use language that the patient understands at a simple level, or use a communication aid, i.e. pictures or symbols. Direct open ended questions to the person and only check out with a carer if something is not clear. Try to maintain eye contact with the person with a learning disability.

Communicating clearly with speech:

- Only use one or two information words in a sentence, and break between each sentence e.g. have you got a pain? Do you want some medicine?
- Use everyday words wherever you can – rather than medical terms. Use very literal language and use direct rather than abstract phrases, idioms or metaphors e.g. 'have you got a pain?' rather than 'how do you feel?' Have only one idea in a sentence;
- Don’t talk too fast, and give the person plenty of time to respond to what you’ve said – it takes time for many people to process the words they hear;
- Check back that the person has understood what you have said – ask them to tell you what they think you said;
- Use gestures when speaking –gestures and facial expressions give visual clues about the meaning of what you are saying;
- Use pictures, symbols or objects in the environment to support what you are saying;
- Think about the environment. If it is too noisy and busy, the person may be distracted and find it harder to concentrate on what you are saying;
- Where possible, take information from the patient’s carers about how much they understand, how they communicate and how to communicate with them.

Supporting people with visual impairment:

- Make handwriting more legible by choosing a dark felt tip pen and write neatly using thicker strokes;
- Show the person where the toilet, call button, etc. are, rather than giving directions;
- Encourage people to bring in their usual aids.

Supporting people with hearing loss:

- Face the person directly – if you look away the deaf person cannot see your lips;
- Speak clearly and at a normal pace – do not shout;
- Use gestures to help explain what you are saying – use gesture, point, mime to help explain what you are saying e.g. show a cup and ask what they want to drink;
- Make sure you have good light on your face – so the person can see your features and read your lips easily;
- Use whole sentences rather than one word replies – lip reading is 70% guess-work and many words look the same. Using sentences gives contextual clues;
- Be patient – if you are asked to repeat something, try changing the sentence slightly, it may make it easier to understand;
- Do not give up – if you cannot make yourself understood then write it down or draw what you mean;
- If the person is a sign language user, they will probably still expect to have to lip-read your reply – very few hearing people sign, and deaf people are used to communicating with hearing people;
- Provide any information in an accessible format;
- Demonstrate any examination or procedure before you perform it.

As with anyone people with a learning disability may get anxious in an unfamiliar health care setting. By demonstrating the examination first you may reduce the anxiety and ensure the examination is complete. A small amount of sedation may be helpful in venesection if the person is needle phobic.

Investigate early as people with learning disabilities often present late with serious illnesses.

Ensure proper diagnostic tests are carried out wherever unexplained symptoms or physical changes are noted. Consider screening tests such as C reactive protein to help detect acute illness.

Avoid diagnostic overshadowing

It is essential that people with a learning disability are afforded the same investigations and tests that any other person would expect to receive where there are symptoms of ill health or clinical indication that there may be an underlying physical health issue. Whilst it is acknowledged that not all people with learning disabilities are able to easily tolerate certain tests it is still vitally important that they are tried and reasonable adjustments are attempted to make them as successful as possible.

Research has demonstrated delays in investigations and tests have directly contributed to the premature death of a person with a learning disability.

Handy Tips

- Contact the acute liaison service to see how they can help the patients whilst undergoing investigations in the hospital setting. Contact the health promotion team or make a referral to the community treatment team for learning disabilities who may be able to support the patient to have the desired tests;
- Do not assume any changes in behaviour or deterioration are caused by the learning disabilities and do not make assumptions or judgements about the person. Try and see the person not the disability;
- Ask and look for signs of pain and distress regularly. Patients with a learning disability do not have a higher pain threshold.
- Pain relieving medication or sedation should be prescribed according to the doctor's normal expectations of the needs or other patients with similar illnesses. As a doctor you need to be proactive and should not wait to be asked. Use a Face scale to assess pain and consider using a trial of a simple analegesic in people with profound communication difficulties;
- Consider mental health issues after excluding a physical health.

People with learning disabilities are vulnerable to mental health problems, particularly how they present, and are assessed and treated. The presentation can make the assessment process more difficult. Some signs and symptoms may appear atypically or be overshadowed by conditions such as autism.

Some clusters of symptoms may suggest particular conditions in individuals, though they do not meet full diagnostic criteria. This may result in the doctor making a diagnosis of an unspecified disorder rather than make a more specific diagnosis – for example, diagnosing ‘personality disorder unspecified’ rather than an exact category, or ‘psychotic illness’ instead of a subtype of schizophrenia.

Involve people with learning disabilities in decisions, and understand the law around capacity and consent.

You must assume everyone has capacity until you demonstrate they do not. CURB is a mnemonic developed to help doctors assess a patient's capacity to make an appropriate decision.

C - Communicate. Can the person communicate their decision?
U - Understand. Can they understand the information you are giving them?
R - Retain. Can they retain the information given to them?
B - Balance. Can they balance or use the information?

Making reasonable adjustments for people with Autism?

- Put an Alert on EMIS indicating that the patient has a diagnosis of autism;
- Telephone triage system – allow the patient to say their name to enable staff to log into system to bring an alert up;
- An alert could include 'this person has' communication difficulties, needs early or late appointment, needs double appointment, unable to talk over phone, bypass triage system and only give GP / Nurse idea of problem, any authorised advocate that can speak on patient's behalf;
- Environment is an important factor. Some people are particularly sensitive to noise, lights, sounds, smells and touch. Sensory issues can contribute to the levels of stress for adults and children with autism;
- Individuals may find it difficult to cope in crowded or noisy waiting rooms. Avoid baby clinic times, flu clinics etc. Try to give appointments at the start or end of surgery;
- Make reasonable adjustments wherever possible. Provide a quiet area in the waiting room, small room or even allowing the individual to wait outside until their GP is ready for the appointment;
- Keep the patient updated if GP / Nurse are running late as they may become more anxious the longer they need to wait;
- It helps if members of staff are patient. It can often take much longer for an individual with autism to answer a question or communicate effectively;
- An individual with autism may need instructions repeated more than once;
- Remember language can be very literal and may need explaining or writing down. Do not assume the person understands what you have said.

Reasonable adjustments for GPs / Nurse and Healthcare Professionals

- Explain verbally and / or in writing what is going to happen during the consultation;
- Ask direct and closed questions – you are much more likely to get a response;
- Delayed processing may mean that you need to wait longer for a response after asking a question;
- Eye contact does not mean someone is listening or that they understand. A lack of eye contact does not mean that the person is not listening to you;
- Speak in short sentences with easy to understand information;
- Language should be kept as literal as possible – jokes, metaphors and sarcasm can be very confusing. Keep gestures and facial expressions to a minimum;
- If the individual permits, ask parents/family/carers for additional information as they are often very knowledgeable about that individual;
- Do not give too many options and write down action points if possible;
- A crowded waiting area, noise and lights may impact on the individual's level of anxiety and effective communication skills;
- Please trust any advice given by autism specialists, family members or named advocates– they will know the person very well.

Personalised reasonable adjustment practice plans

Following on from understanding the need to make generic reasonable adjustments across the practice environment, there will also be a requirement to personalise plans for reasonable adjustments to be made for an individual with a learning disability. Currently practices are aware of most people who have a learning disability on their registers and in Sunderland they are updated and agreed annually with the primary health facilitation nurse. Practices need to ensure they are familiar with their learning disabled patients and know in advance of any appointments that they know what reasonable adjustments will be required to meet the individual's needs successfully. This information can be gained by speaking with the primary health facilitation nurses, link nurses, community nurses and carers. Over the next 3 years it is hoped that practices will be able to flag on the system, what personal reasonable adjustments are required to an individual's appointment and care and build a personal profile.

A personalised plan could easily be constructed to meet the needs of an individual with autism. Many of the adjustments above will meet the needs of most individuals with autism.

Emergency Health Care Plans

An emergency health care plan (EHCP) makes communication easier in the event of a healthcare emergency.

The principles of writing and using an EHCP are fully described on page four of the Deciding Right EHCP document. http://www.nescn.nhs.uk/wp-content/uploads/2014/06/EHCP-NHS-Fillable-form-v14-April-2013.pdf

These notes are intended as a practical guide to discussing and documenting an EHCP, and include an EHCP document with advisory notes in each of the domains.

- If the individual has capacity for these decisions: the discussion is one of shared decision making;
- If the individual wishes, this may include the parents (for children), partner or relatives;
- If the individual lacks capacity for these decisions: any decisions must be made following the nine point checklist of the Mental Capacity Act: Refer to the section on Mental Capacity Act.

The plan should:

- Include a brief summary of the individual's diagnosis/es and their understanding of it;
- Include a list of regular and prn medications, and indications for any rescue medications left in the patient's home for emergency use;
- Indicate any ceilings of care that have been requested by the patient and any that have been recommended by healthcare professionals;
- Describe actions for emergencies arising at home.

Further resources to aid completion of emergency healthcare plans, including useful phrases to use, can be found on the above website, or on their app which can be downloaded to smartphones and tablets. An emergency health care plan could be developed following a MDT held in general practice where patients who are risk of admission are discussed.

People with autism or a learning disability may already have a WRAP plan (Wellness and recovery action plan). This should be held by them or their carers and will offer guidance of what needs to happen in a crisis situation. Primary care need to be aware that these plans are available. This could be included in a more in depth personal profile and it is hoped this will become available for people with autism soon.

Easy Read Documentation

It is really important that primary care ensure information is given to people with a learning disability in a format that makes it easier for them to understand. This would be common practice when providing information to a patient whose first language may not be English, so the same consideration needs to be afforded.

It can be difficult as sometimes information is promoted as being accessible or easy read when in fact it is not, so it is often useful to ask people with learning disabilities to scrutinize what you intend to provide to get a measure for its accessibility.

In Sunderland we have a dedicated website for people with a learning disability, their carers and all health professionals. The website is a fantastic resource and holds the following information:

- Primary Care Information;
- Secondary Care Information;
- Specialist Information.

The aim of the website is to ensure the information is local and meaningful for its users. The website is used as a platform to share news and developments in learning disabilities, share resources, provide easy read information and guidance on health agendas for this group of people.

It also has the facility built into it to be able to narrate the information by clicking on the SPEAK UP link, this is especially useful for people who do not read or have a visual impairment.

The website is constantly being developed as more services are keen to provide their information in an accessible format, so please check it periodically to see what has been added.

It is essential that all practices are aware of this website as useful resources are held on here that demonstrate best practice. It has processes to follow in relation to NHS screening programmes for example and provides the primary care with resources to use such as easy to understand flu invite letters.

Lead GPs, Practice nurses and Healthcare assistants who are providing annual health checks need to use the resource within their consultation as it will provide the required health action plans needed for the check itself.

Even highly verbal individuals with autism would also benefit from information being presented to them in an easy version, or at least being offered the opportunity to have the information in an easy read format. Having information in an easy read format will enable them to process information, when they are feeling anxious or stressed. Verbal ability and the ability to communicate effectively is the first thing to be affected, when someone with autism is experiencing high levels of anxiety. Many people with autism think in pictures, regardless of their verbal ability, and so an easy read version would aid them to process important information.

Who should be referred to the IMCA service?

The local authority/NHS decision maker **MUST** refer you if you have no ‘appropriate’ family and friends if you lack capacity to make a decision about either:

- Serious medical treatment;
- Long term moves (more the 28 days in hospital/8 weeks in a care home);
- Deprivation of Liberty Safeguards.

The local authority/NHS decision maker **MAY** refer you if you lack capacity to make a decision about either:

- Care review - with no ‘appropriate’ family or friends;
- Safeguarding referral - victim or alleged perpetrator, regardless of family and friends.

The IMCA service in Sunderland is provided by Total Voice who are based at the following address:

Total Voice Sunderland
VoiceAbility,
1d North Sands Business Centre,
Liberty Way,
Sunderland,
Tyne & Wear,
SR6 0QA

(0191) 510 5051

Quality Checks

Over the past 10 -15 years there have been a number of reports which inform us that there is a need to improve services for people with learning disabilities for example: Death by indifference (2007) and Transforming Care (2012).

The Health Quality Checkers team are made up by people with a learning disability; these individuals have personal experiences of using or caring for someone who uses health & social care services.

They know how health services should support people with learning disabilities and they are experts by experience. The heath quality checkers approach is different from that of the formal inspections that services receive because people with learning disabilities take the lead and use the “Good health standards for all”. They check services against these 5 standards that are important to people with a learning disability to help gain better understanding of what practices need to improve on.

6) Standardisation of Care / Good Practice

Consent Pathway

The ‘Mental Capacity Act’ is an important law for people with a learning disability. It helps make sure that people who may lack capacity make their own decisions and get the support they need to make those decisions. Where they are not able to make their own decision, it says a decision must be made that is in their ‘best interests’.

What does 'mental capacity' mean?

Mental capacity is the ability to make an informed (having appropriate information) decision based on understanding a given situation, the options available, and the consequences of the decision.

Just because someone is not able to make one decision, this does not mean they can’t make other decisions. People should always support a person to make their own decisions if they can do so.

What is the Mental Capacity Act?

The Mental Capacity Act 2005 is a law that protects vulnerable people over the age of 16 around decision-making. It says that:

- Every adult, whatever their disability, has the right to make their own decisions wherever possible;
- People should always support a person to make their own decisions if they can. This might mean giving them information in a format that they can understand (for example this might be easy read information for a person with a learning disability) or explaining something in a different way;
- But if a decision is too big or complicated for a person to make, even with appropriate information and support, then people supporting them must make a ‘best interests’ decision for them.

What is a 'best interests' decision?

This means they make the decision on behalf of the person, but in making the decision, they must do so in the person’s ‘best interests’.

They must involve the person as much as possible in working out what the right decision is and involve others who know them well, such as family and friends.

The 5 main principles of the Mental Capacity Act:

- Everyone is believed to have capacity to make decisions unless it can be proved that they do not;
- A person should be supported to make their own decisions using all practicable steps before it is decided that they are unable to do so;
- A person should not be considered unable to make a decision simply because their decision is considered unwise or eccentric by others. (If capacity is in doubt at this stage and the person has a disorder of the mind, no matter how caused, use the four point capacity test below);

- Any decision made on behalf of someone who lacks capacity must be made in their best interests;
- Any best interests' decision must take account of all the circumstances and take the least restrictive course of action available to maintain the person's basic rights and freedom.

Supporting someone to make a decision

Before deciding that someone lacks the capacity to make a decision, all practical and appropriate steps must be taken to help them make the decision themselves.

The Mental Capacity Act Code of Practice is important guidance on how the law should be applied in particular situations. It includes a summary about how to help someone make a decision in four main principles:

Provide relevant information

- Does the person have all the relevant information they need to make a particular decision?
- If they have a choice, have they been given information on all the alternatives?

Communicate in an appropriate way

- Could information be explained or presented in a way that is easier for the person to understand (for example, by using simple language or visual aids)?
- Have different methods of communication being explored if required, including non-verbal communication?
- Could anyone else help with communication (for example, a family member, support worker, interpreter, speech and language therapist or advocate)?

Make the person feel at ease

- Are there particular times of day when the person's understanding is better?
- Are there particular locations where they may feel more at ease?
- Could the decision be put off to see whether the person can make the decision at a later time when circumstances are right for them?

Support the person

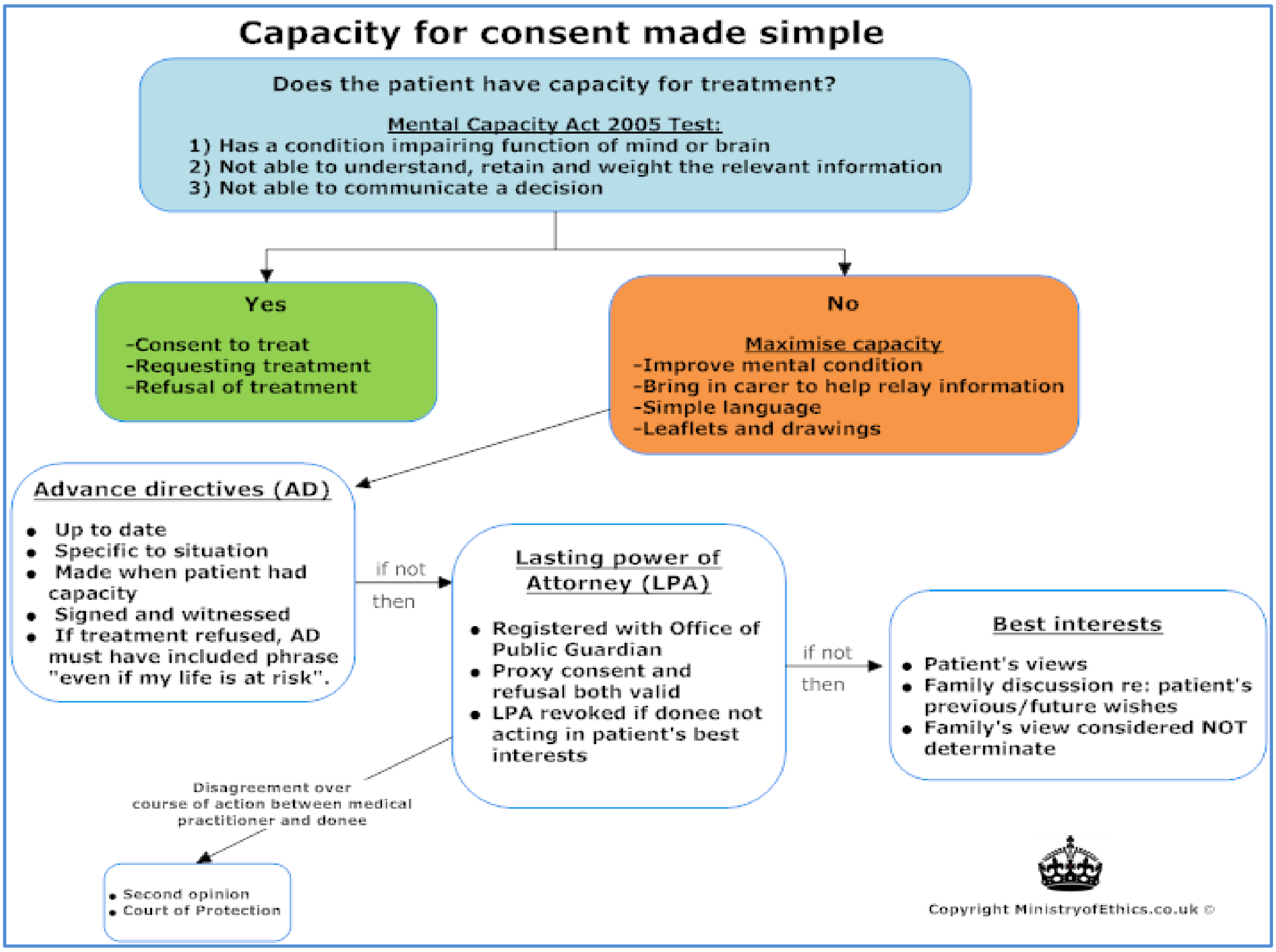
- Can anyone else help or support the person to make choices or express a view?

How is capacity assessed?

To have capacity to make a particular decision at a given time a person must be able to:

- Understand the information relevant to the decision, including the reasonably foreseeable consequences of making or not making the decision;
- Retain that information long enough to make the decision;
- Use or weigh the information as part of the decision making process;
- Communicate the decision in any recognisable way.

Failing any one of the above means the person lacks the capacity to make this decision this time. Please see **Appendix 5** the 5 Principles of the Mental Capacity Act 2005.



Making a best interest's decision

If, after all steps have been taken to support someone to make their own decision, the person is assessed as lacking capacity to make that particular decision, then a 'best interests' decision must be made.

The person who makes the 'best interests' decision is called the 'decision maker'. Who the decision maker is will depend on the situation and the type of decision. For example:

- For most day-to-day decisions the 'decision maker' is likely to be the person who is supporting the person;
- Where it is a decision about healthcare it will be the relevant health professional.

Whoever is the decision maker, it is important they talk with others involved with the person, and involve the person themselves as much as possible, to get a good understanding and therefore make the best decision they can.

Best Interests checklist

The full checklist is in the Mental Capacity Act Code of Practice. The Mental Capacity Act sets out a best interest's checklist, which must be followed when making a best interests decision:

- Will the person regain capacity?
- Involve the person;
- Consult all relevant people.
- Consider all the information.
- Do not make any assumptions.
- Consider past, present and future wishes.
- The very least restrictive option.

What decisions can be made under the Mental Capacity Act?

These can be everyday decisions about what to eat or what clothes to wear - family, carers and support workers may assess capacity often and support people to make their own decisions like this.

Some decisions are more significant such as where to live, how to spend large amounts of money or what medical treatment to have. Professionals may be involved in assessments which include these bigger decisions.

What decisions can't be made?

Decisions that cannot be made for another person under the Mental Capacity Act include the decision to get married or consenting to sex. Read the Mental Capacity Act Code of Practice for full information on this. Involve the person you are making a best interests decision for. When a best interests decision is being made the person must still be involved as much as possible. Mencap and BILD's Involve Me resource is about creative ways that can be used to ensure people remain at the heart of decision making, and how their preferences can be captured and used to influence decisions about their lives even if they lack capacity to make the decision.

Independent Mental Capacity Advocate (IMCA)

If a person has no family or friends for the decision-maker to consult with on important decisions like serious medical treatment or changes of accommodation, then an Independent Mental Capacity Advocate must represent the person's views. They are a legal safeguard for people who lack the capacity to make big decisions. The Mental Capacity Act 2005 ensured there was a robust framework provided to help practitioners navigate their way through informed consent, assessing capacity and making best interest decisions on behalf of their patients. The following link can be copied and pasted to find out more about the act, the principles and how to implement it in practice.

What we should be considering for patients with a learning disability who may or may not lack capacity to be involved in their health care treatments. Capacity and consent will be covered as part of the training that will be delivered.

Pre-Check Annual Health Check Questionnaires

Several practices in Sunderland send out a pre check questionnaire that allows some of the information that informs an annual health checks to be collated prior to the appointment. This is good practice as it allows more time to be spent during the health check at the practice carrying out clinical examination, medication reviews, referrals and health promotions tasks.

Annual Health Checks

The Annual Health Check scheme is for adults and young people aged 14 or above with learning disabilities who need more health support and who may otherwise have health conditions that go undetected.

Who is eligible for an Annual Health Check?

People aged 14 and over who have been assessed as having moderate, severe or profound learning disabilities, or people with a mild learning disability who have other complex health needs, are entitled to a free annual health check. The Annual Health Check is also a chance for the person to get used to going to their GP practice, which reduces their fear of going at other times.

What are the benefits of an Annual Health Check?

People with learning disabilities often have difficulty in recognising illness, communicating their needs and using health services. Research shows that regular health checks for people with learning disabilities often uncover treatable health conditions. Most of these are simple to treat and make the person feel better, while sometimes serious illnesses such as cancer are found at an early stage when they can be treated:

What should happen at an Annual Health Check?

The Annual Health Check lets the person with learning disabilities go to their GP practice and have aspects of their health checked. It also allows them to talk about anything that is worrying them. During the health check, the GP or practice nurse will carry out the following for the patient:

- A general physical examination, including checking their weight, heart rate, blood pressure and taking blood and urine samples;
- Assessing the patient’s behaviour, including asking questions about their lifestyle, and mental health;
- A check for epilepsy;
- A check on any prescribed medicines the patient is currently taking;
- A check on whether any chronic illnesses, such as asthma or diabetes, are being well managed;
- A review of any arrangements with other health professionals, such as physiotherapists or speech therapists.

If the person's learning disability has a specific cause, the GP or practice nurse should do extra tests for particular health risks. For people with Down's syndrome, for example, they should do a test to see whether their thyroid is working properly.

The Annual Health Check may also be a good opportunity to review any transitional arrangements that takes place when the patient turns 18. The GP or practice nurse will also provide the patient with any relevant health information, such as advice on healthy eating, exercise, contraception or stop smoking support. Further information can be gained from the Step by Step Guide to Annual Health checks produced by the Royal College of General Practitioners. There is an action plan in the appendices of this document that highlights what we need to do to improve the annual health check scheme in Sunderland.

Step by Step Guide to annual health checks

Locally – There are a team of health promoters who are based at Monkwearmouth Hospital who can be contacted to support people with a learning disability to their annual health check appointment, where there appears to be issues with access or understanding.

They can be emailed directly on the following addresses:
graeme.fergurson@ntw.nhs.uk
emma.reid@ntw.nhs.uk
margaret.mather@ntw.nhs.uk
helen.wharton@ntw.nhs.uk

Health Action Plans

A Health Action Plan is something that people with a learning disability should have.

It is an accessible plan that belongs to the person that says:

- What things they are doing to keep fit and well;
- What other things they want to do to be healthy;
- What help they may need to keep healthy.

It helps people to make sure that they have thought about their health and that their health needs are being met.

Why have Health Action Plans?

- Good health means being well in your body and in your mind;
- People with learning disabilities sometimes have more health problems than people without a learning disability;
- Some people with a learning disability find it hard to access mainstream health services and that sometimes their health needs are not met;
- People with learning disabilities have the right to be as healthy as we can be. A Health Action Plan will help the person to be healthy;
- Doing a Health Action Plan gives the person the opportunity to take control over their own health and encourages people to make healthy choices.

Who should have Health Action Plans?

Everyone with a learning disability should be asked if they want a Health Action Plan. They do not have to have one if they do not want one. It is a good idea for someone with a learning disability to have a Health Action Plan:

- If they need a lot of help to be healthy;
- If they have a lot of health needs;
- If things are changing in their life;
- If they are getting older.

Health Action Plan Examples

After visiting a practice nurse for a health check Simon was supported by the smoking cessation nurse to help him cut down. Simon was identified to have high cholesterol and was supported to improve his diet and do more exercise.

Simon was referred to the learning disability service who talked to him about testicular awareness and self-examination.

Handy Tips

- Health Action Plan templates can be downloaded from Sunderland Action for Health Website. Along with the actual plans there are also "fact" sheets that help people with learning disabilities learn more about their health;
- There are 21 different aspects of health that relate to the plan however the health issues that are identified either at the annual health check or other appointments are the ones that will need a plan;
- The Health Promotion Team can also assist general practice with the development of health action plans;
- Always remember to ask the person if they already have a health action plan as the health needs may have already been identified and a plan developed to meet their needs.

Flu Immunisations

The Community Treatment Team for Learning Disabilities in Sunderland have agreed to work in partnership with Sunderland Clinical Commissioning Group to support the GP practices with difficult to reach, complex patients who may not ordinarily have their flu vaccine. A separate action plan has been developed and implemented to support this across the city.

This protocol will simply outline the process and arrangements for obtaining the flu vaccine from the practice to administer to the patient and the documentation in relation to the administration of it:

- The GP practice will contact IRS on 0303 123 1145 if they wish to make a referral for a patient to have their flu immunisation where it has not been possible to administer at the practice or patients home. A list of reasonable adjustments is included in **Appendix 6** the Flu Protocol;
- The GP practice will ask if the patient is already known to the learning disability team, if they are IRS will simply email the allocated professional who will make the necessary arrangement's to have the flu vaccine given by a trained nurse;
- If the patient is not known to the community treatment team then IRS will open the referral and email Ashley Murphy who will coordinate the new referral and ensure it is allocated.
- IRS will ask the GP practice a series of questions to check out that all reasonable adjustments have taken place first;
- Once the learning disability nurse has been allocated to the patient, they will take responsibility for visiting the practice with the relevant documentation. This document will be completed to say they have collected the flu vaccine, with details of the batch number;
- If the administration of the vaccine is successful the nurse will then electronically send the document back to the practice so the records can be updated to reflect the vaccine has been given. Equally if it has not been successful the practice will be informed and the vaccine returned or disposed of accordingly.

The Role of the Health Promotion Team in this project is:

- The health promotion team are working with each practice across the city to help each practice to identify people with learning disabilities on their register who have not had the vaccine in the past;
- Once this has been done the practice will seek consent from the patients and those who know them best to establish if they would like the health promotion team to become involved to help them either access the clinic or additional support to help them become less anxious for example via the community team;
- It maybe that they can support them to visit the practice, explore their anxieties, help them to understand and if not they will ask the nurses within the community treatment team to administer the vaccine where possible;
- We have a flu plan **Appendix 7** in Sunderland that has been developed in partnership with the CCG and NTW. Please see appendices for a copy of the flu plan **Appendix 7** for 2016/2017;
- In 2015 only 43% of people with a learning disability received their flu vaccine. We have made a pledge to increase this by at least 20% this year;
- This can only be achieved if we work closely together and GP practices obtain consent for NTW to contact patients directly to offer support;
- We need to remember that all people with a learning disability have been placed in a high risk group and are entitled to the offer of a flu vaccine;
- NTW are working closely with the CCG and advising them monthly of how many people have been vaccinated whilst offering continuing support to deliver the program to more complex patients.

Handy Tips

- Remember there is a Health Promotion Team in Sunderland that can take referrals to offer people support to access the practice for their flu vaccines where they require additional support or a referral can be made for trained nurses at NTW to offer the flu vaccine;
- It is now possible to offer a patient who has a learning disability or autism the intranasal spray where they have needle phobia as a reasonable adjustment;
- Communications have been circulated regarding this and excess stocks not used for children can be utilised.

Maternity Services and Midwifery

- In 2015 a report was written called Hidden Voices **Appendix 8**. NHS England supported CHANGE and PEN to do this. This explored the inequities in maternity services for people with a learning disability and unfortunately reports the poor experiences expectant parents had. There were several recommendations made and these can be seen in the report in **Appendix 5**.
- Over the next 12 months specialist services, primary and secondary care will work jointly as a region and then locally to meet some of the suggested recommendations going forward.

Please see quote below from a person with a learning disability involved in writing the report;

"I think midwives should be trained in how to deal with people who have learning disabilities because I just feel as though, when someone hears the word disabled or learning disability, people don't understand what it is and just think that you're stupid or label you and treat you as though you don't exist."

Midwives / Autism

Autistic women report the need to feel more empowered and for more information about their birthing day. Their experience is reliant on three factors including; clear communication, sensory adjustments and change management. In their own words, autistic women describe their experiences.

Communication

During pregnancy individuals need to be reassured more than usual, they need to understand clearly each stage to reduce anxiety.

If there is a change in midwife provision and another midwife is taking over their care this needs to be managed carefully and via a transition plan, it's not as simple as stating what's going to happen then the new midwife starts.

Literal Interpretations

This is a real example of a literal interpretation by someone who has autism:

"I was told to push again for next delivery when I asked why they said "second baby" and laughed - they meant placenta but I was terrified as I thought they meant twins"

Health Breast Screening

Sunderland CCG has currently got a LIS in place which was developed to support the uptake of all screening programmes. Please see appendices for details of this LIS. We will add to this in the coming months and offer support from the Health Promotion Team to all GP practices who have identified ladies with a learning disability who requires advice and support to enable them to attend for their mammograms.

Easy read information about breast screening and a regional pathway is also available on Sunderland Action for Health.

An annual Health check is a good opportunity to ensure if the patient is eligible to go for a mammogram and to check that she has attended. If not a plan should be put in place wherever possible to support the patient to attend. The Health Promotion team can assist with this.

Bowel Screening (home kit / bowel scope)

A project was developed in 2016 in South Tyneside that looked to improve the uptake of bowel screening for people with a learning disability. It is hoped that in 2017 the Community Learning disability Team can work closely with the Cancer Lead in the CCG to become involved in the same project with the view to increasing the uptake of bowel screening.

Training is being offered to social care providers who have responsibility to encourage the people they care for where eligible to participate in the programme by helping them to understand the reasoning behind it and the benefits it can have.

The health professional in primary care should be checking the status of the person at their annual health check as to whether they have had bowel screening and if not offering support to engage with it.

Please see **Appendix 9** for details of the project that ran in South Tyneside.

Cervical Screening

A number of studies have identified a low uptake of cervical screening in women with learning disabilities, ranging between 13% and 25%. A study carried out by MENCAP in 2000 revealed that out of 560 women aged 20 - 70 years; only 25% had ever had a cervical smear. The majority of the remaining 75% had been "ceased" by their General Practitioner.

The term 'ceased recall' is used by the NHS CSP to identify women whose name has been permanently removed from the recall system.
Women can choose to be ceased from recall for clinical reasons. A high number of women with learning disabilities are ceased from the cervical screening programme.

A study in Shropshire highlighted that the main 'clinical reasons' why women with a learning disability were ceased from CSP were:

- Low or no sexual activity;
- Unable to understand the procedure or give consent to undertake the procedure;
- Due to their ‘medical condition’.

Having a learning disability alone is not a valid reason for ceasing women from the programme. Nor can a parent or carer make this decision on behalf of an adult woman. It must be assumed that every adult has the capacity to consent until proven otherwise. The woman should be assisted in making an informed choice about whether or not to participate in the programme.

Families / carers may feel that if the woman is not sexually active they do not need to have a cervical screening; however how do their families / carers always know whether they are or are not sexually active and at the end of the day woman need to be screened whether or not they are sexually active.

Accessible, easy read materials are available to maximise capacity and assist understanding.

Recommendations:

- Smear takers need to be aware of the needs of women with learning disabilities by introducing specific training as part of the local screening education programmes, (which would include consent issues and ceased recall);
- All general practices and providers who undertake smears should follow the guidance, ‘Good Practice in Breast and Cervical Screening for women with learning disabilities’. (NHS Cancer Screening Programmes October 2000) www.cancerscreening.nhs.uk;
- The NHSCSP Good Practice guidelines should be readily available in all practices and provider work places offering cervical screening;
- Easy read information packages should be made available to women with learning disabilities to help them to fully understand the procedure.

Handy Tips

- Information available from the Health Promotion Team and Sunderland Action for Health is available.

Cervical Screening Information

Invitations to the practice for cervical smear tests need to be simple and clear and easy to read with pictures illustrating the message.

- Effective preparation before the procedure will minimise individual’s anxieties and fears.
- Eligibility for the cervical screening programme must be a carefully made, multidisciplinary decision.
- Extra time for preparation and explanation of the procedure should be given.

AAA Screening

Abdominal Aortic Aneurysm screening is a free National Screening programme where all men aged 65 plus are screened to check if they have an abdominal aortic aneurysm. The screening is by invitation and consists of an ultrasound scan.

The North of England Screening Programme is run from The Queen Elisabeth Hospital Gateshead. Tel (0191) 445 2554

Diabetic Eye Screening

South Tyneside Foundation Trust delivers a Diabetic Eye Screening Service in Sunderland. The service offers a reasonable adjusted approach for people with a learning disability who have diabetes.

This was achieved when the learning disability team based in South Tyneside shared their learning disability registers for those with a learning disability and diabetes. This enables them to target those people and send them easy read appointment letters and make reasonable adjustments to their care, if required.

This could be explored and a similar approach for patients in Sunderland could be considered once information sharing has been discussed and agreed.

Post-Check Questionnaire

There is an opportunity after a person with a learning disability has their annual health check to complete an online questionnaire called Rate My Check. This can be found on the primary care section of Sunderland Action for Health. Health Professionals carrying out the checks need to show the patient and/or their carer where this can be found. Results are collated by Sunderland People first and feedback will be available.

Flagging of Patients with Learning Disabilities / Autism

All people with a learning disability are registered with the practice. The Health Facilitator visits each practice in Sunderland at least once a year to ensure the register is accurate. Sometimes people have been incorrectly coded for example they have a learning difficulty rather than a disability or they would be better placed on a mental health register. Currently there is not a separate register for people who have autism. This is an area that Sunderland would like to ensure is developed so there is a complete register for those with a learning disability and a separate register for those with only autism.

The Role of the Nurse in General Practice

Our code of practice contains a series of statements which signify what good nursing practice looks like. The code for ‘prioritising people’ is certainly relevant to our role when caring for patients with a learning disability and or autism. We are expected to treat people as individuals whilst upholding their dignity.

Great emphasis is placed on being kind, respectful, compassionate and professional. As nurses we should not find any of this a problem, however, we may find the following expectations more difficult, for example:

- Avoid making assumptions and recognise diversity and individual choice, respect and uphold people’s human rights;

- As human beings we can all be guilty of making assumptions regarding our patients.

Also it is very difficult to assess when someone with a learning disability and or autism is able to contribute to their care and when they need us to be an advocate.

If we are struggling at this point it may be helpful to work in partnership with others to ensure deliverance of most effective care.

The four principles of the 2001 white paper ‘valuing people’ are:

- Right;
- Independence;
- Choice;
- Inclusion.

These four principles would probably be thought of as social expectations but they should also be applied to health.

Our patient’s with a LD and or autism have a RIGHT to the same National Health Services as any other patient without prejudice, judgement and or ignorance.

We should treat them independently, looking at and meeting their individual needs.
They should, where appropriate, be encouraged to make health related choices after being given the information in a way they can understand.

They need to be included in health screening, health improvement, health optimisation.
Approach to care, needs to be person centred, we can as nurses have a huge impact on the healthcare experience, quality of life and mortality of the patient with a LD and autism.

There is a growing research evidence base illustrating these patients are experiencing higher and unmet health needs.

‘Nursing is the use of clinical judgement in the provision of care to enable people to improve, maintain or recover health, to cope with health problems and to achieve the best possible quality of life, whatever their disease or disability until death.’(RCN 2007).

We are used to working with people who have a health need or a health related problem but a patient with a LD and or autism may also have problems with, perception, cognition, memory, attention, language and have sensory sensitivities.

Reasonable adjustments can be made on an individual basis; we can ask family members, carers, support staff and other agencies for some background information in order to help us provide the best environment thus enabling us to provide optimal care and assessment.

We have a duty of care to all of our patients and we should not assume, that a patient with a learning disability and or autism are too ‘difficult’ or too ‘diverse’ to include in our busy daily lives in general practice.

The Role of the GP in General Practice

Patients with learning disabilities represent a small but significant proportion of a GP's caseload. Patients with learning disabilities have an increased incidence of psychiatric illness, epilepsy and behavioural difficulties. Morbidity and mortality rates are considerably increased and life expectancy significantly reduced.

In managing patients with learning disabilities, GPs need to be aware of likely associated conditions and knowing where to obtain specialist help and advice, understand how psychiatric and physical illness may present atypically in patients with learning disabilities, and use additional skills of diagnosis and examination in patients unable to describe or verbalise symptoms.

In order to deliver dignified, respectful and compassionate care you will need to take extra time: Arranging the appointment to see you as a doctor may have required considerable effort for the person with a learning disability and their carers. Try to offer double the usual appointment, outpatient time or consulting time and be mindful that many carers will have other commitments. People with learning disabilities say that negative or unhelpful attitudes of health care workers deter or stop them from seeking help.

Use language that the client understands at a simple level, or use a communication aid, i.e. pictures or symbols: Direct open ended questions to the person and only check out with a carer if something is not clear. Try to maintain eye contact with the person with a learning disability.

Demonstrate any examination or procedure before you perform it: As with anyone people with a learning disability may get anxious in a an unfamiliar health care setting. By demonstrating the examination first you may reduce the anxiety and ensure the examination is complete. A small amount of sedation may be helpful in venesection if the person is needle phobic.

Investigate early as people with learning disabilities often present late with serious illnesses: Ensure proper diagnostic tests are carried out wherever unexplained symptoms or physical changes are noted. Consider screening tests such as C reactive protein to help detect acute illness.

Ask and look for signs of pain and distress regularly. Patients with a learning disability do not have a higher pain threshold: Pain relieving medication or sedation should be prescribed according to the doctor's normal expectations of the needs of other patients with similar illnesses. As a doctor you need to be proactive and should not wait to be asked. Use a Face scale http://wongbakerfaces.org/ to assess pain and consider using a trial of a simple analgesic in people with profound communication difficulties.

Consider mental health issues after excluding a physical cause: People with learning disabilities are vulnerable to mental health problems, particularly how they present, and are assessed and treated. The presentation can make the assessment process more difficult. Some signs and symptoms may appear atypically or be overshadowed by conditions such as autism.

Some clusters of symptoms may suggest particular condition in an individual, though they do not meet full diagnostic criteria. This may result in the doctor making a diagnose of an unspecified disorder rather than make a more specific diagnosis – for example, diagnosing 'personality disorder unspecified' rather than an exact category, or 'psychotic illness' instead of a subtype of schizophrenia.

The Role of a HCA in General Practice

The Health Care Assistant has a role to play in the care of a patient with a learning disability and or autism. The HCA needs to understand the individual needs of his/her patient and be adaptable in making reasonable adjustments in order to provide the best most achievable care possible for all patients.

When involved in Health Checks for patients with a learning disability and or autism they need to provide care within their own competencies and be aware when to refer onto other healthcare professionals.

HCA's are not presently accountable in the same way nurses and doctors are but the RCN states they need to be a safe, person centred care provider who works as part of a team to deliver high quality, ethical and non-discriminatory care to patients and clients.

HCA's have their nursing tasks delegated and should be supervised by registered professionals.

They need to be guided by protocols and act within these protocols at all times. They should only perform tasks within their training and competency levels.

They must demonstrate competence supported by their level of knowledge and training before being delegated particular tasks. They have a duty to inform the delegating professional if they aren't competent to perform a requested task.

They should not be required to make 'standalone' clinical judgements and plan the care of patients based on these judgements.

HCA's however, like all health workers within the NHS need to be aware of equality, diversity and rights.

The role of a Receptionist in General Practice

Receptionists are often the first person patients see. They use customer service and admin skills to welcome people into the practice. As a receptionist, you're often the first person that patients meet when they come through those doors. Receptionists often:

- book patients in for appointments;
- enter patients details onto computer systems;
- direct patients where to go within the practice.

As well as dealing with patients face-to-face, receptionists often:

- answer phones, sometimes directing calls to other staff through the switchboard or phone system;
- book appointments by phone;
- answer queries from patients and other staff;
- some receptionists combine the job with other admin duties throughout the practice.

Patients and their relatives can be nervous or upset when they visit a hospital or clinic so as a receptionist, you may have to calm them down or reassure them. Some receptionists may combine the job with other admin duties, such as:

- filing;
- chasing up reports;
- photocopying;
- inputting data;
- ordering stationery;
- word processing.

Some receptionists work with clerks, health records staff and other admin staff. Depending on where you work, you'll have contact with healthcare professionals.

Receptionists need to:

- be flexible to the needs of the individual they are speaking to either face to face or over the telephone;
- be friendly and welcoming;
- be patient and understanding;
- follow instructions and procedures;
- work accurately and methodically;
- work in a team but use their own initiative;
- work with all types of people;
- deal with people who may be angry or upset;
- be confident using the phone.

Receptionists often juggle many tasks at once therefore it’s important for them to have:

- organisational skills;
- good communication skills;
- IT skills;
- excellent customer service skills.

Care Co-ordination

If a person with a learning disability is known to the community treatment team in Sunderland then they will either have a care coordinator or a lead professional responsible for their care. This person will be responsible for assessments, implementing care plans and evaluating care. This is the first point of contact if you want to discuss any issues or need support or advice. If you do not know who the care coordinator is you can ring the IRS (Initial Response Service) on 0303 123 1145 and they will contact that person and will let them know you are trying to contact them.

Electronic Health Equality Framework

This is an outcomes measuring tool that will be led primarily by the community learning disability team for learning disabilities. It will measure five determinants of health and will flag up areas of potential inequalities where other services such as primary care and social services will need to put strategies in place to ensure unmet health and social care needs are met. Primary care need to be aware of the framework, currently it is a CQUIN target for NTW and where unmet health needs are identified they may need to liaise with primary care to devise a collaborative plan for improvement to that health outcome for the individual.

Please see **Appendix 10** for PowerPoint presentation regarding the EHEF.

Medication (Call for Action Psychotropic Medication)

"Used well and appropriately these medicines [psychotropic] have a place in clinical care. Used poorly and inappropriately, they can take the form of restraint or "chemical cosh". ***Winterbourne Medicines Programme – NHS Improving Quality Report (published June 2015)***

There is an expectation arising from the Winterbourne Medicines Programme and NICE (Learning Disabilities: Challenging Behaviour 2015) and several subsequent guidance documents, that people with a learning disability in receipt of psychotropic medication - who do not have a mental health condition diagnosed - should have an enhanced medication review. Nationally there are additional expectations that the reviews will lead to a reduction in the use of psychotropic medication.

The use of this medication is often described as being for behaviours that challenge. An enhanced review would consider the current benefits and disadvantages of prescribed medication in light of current best practice and with consideration to the patient's capacity and consent and best interest decision making.

The medications of interest are anti-psychotics, anxiolytics, anti-depressant, lithium and anti-epilepsy drugs (AEDs) when used as mood stabilisers.

A presentation was delivered at the TITO event in January 2017 where Dominic Slowie, National Clinical Advisor (Learning Disability & Premature Mortality), updated all Sunderland practices on the plans the CCG has in place to help support practices through this process.

NTW Positive Behaviour Support (PBS) team are carrying out a pilot project regarding implementation of the toolkit in general practice, they are currently working with Chrissie Todd who's practice has agreed to be the test site for this project.

We ask practices not to start this work alone, this is not going to happen overnight and we would like everyone to wait for the test practice pilot to be completed. Future communications around next steps will come from the Medicine Optimisation Team and you will be supported to take this work forward.

The following information will be a useful resource for practices; you will find them all in the appendices section:

Appendix 11 - NICE (2015) Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges - guidance (NG11) National Institute for Health and Care Excellence. www.nice.org.uk;

Appendix 12 - Royal College of Psychiatry (RCPsych). (2016) Psychotropic drug prescribing for people with intellectual disability, mental health problems and/or behaviour that challenges: practice guidance. FR/ID/09

Appendix 13 - NHS England (July 2015) The use of medicines in people with learning disabilities. Letter signed by Dominic Slowie and Keith Ridge. Public Gateway Reference 03689

Appendix 14 - Care Quality Commission (Sept 2015) Brief guide: psychoactive medicines (Learning Disabilities)

NE Pilot Mortality Reviews

Typically people with learning disabilities die prematurely, it is argued from sometimes preventable causes. The North East and Cumbria region were involved in a pilot that reviewed a sample of deaths of people with a learning disability; in Sunderland these reviews took place in City Hospitals. Following on from this the University of Bristol have rolled out the LEDER function which is now a national function to review the deaths for people aged between 4 and 74 in England.

There is an expectation that reviewers will be trained across Sunderland to undertake reviews and a local area contact has been appointed who is currently the Director of Nursing for the CCG. There are still some ongoing issues with resources, training and information governance to clarify but it is agreed that it is the right thing to do so we can begin to learn lessons from these deaths and create action plans for improvements. Please see **Appendix 15** the communication strategy in regards to this.

Audiology / ENT pathway

There is a dedicated pathway for GPs who need to refer a patient with a learning disability where they suspect a hearing loss. It is evident that almost 7 out of 10 people with a learning disability have a degree of hearing loss, often it has not been identified and referrals have not been made for hearing tests and devices. It is often believed that people with a learning disability cannot comply with testing or they would find it difficult to wear devices, this is not accurate. There is a bespoke dedicated clinical service at the audiology department in City Hospitals who have developed an excellent model of care to address this issue. They can be referred to directly via choose and book. Primary care is encouraged to contact the health promotion team if they would like further advice in regards to this. Please see **Appendix 16** for presentation from previous TITO re hearing and referral process.

Community Dentistry Pathway

We are fortunate in Sunderland to have a fantastic community dentistry service. NTW and Dentistry have worked in collaboration for many years to develop robust pathways to ensure people with a learning disability can access dental services. Once a patient has been referred to dentistry because they have complex needs, the dental department will often contact the Acute Liaison Service at city hospitals where a team of two learning disability nurses will help develop a care plan to support their admission through the Department of Same Day Admissions (DOSA) There has been many successful admissions and the MDT across primary, secondary and specialist services have worked in partnership for the best outcome for the patient. A copy of the referral form for community dentistry can be found in **Appendix 17** of this document. There is also an easy read leaflet about what a patient can expect from community dentistry on the Sunderland for Action for Health website.

Community Treatment Team Role & Referral route

There are many people with a learning disability in Sunderland that are not known to the community Treatment team for learning disabilities as they do not need to be. However the service is available for times when a person and their families require support, advice, education, intervention, assessment with a particular issue. The Community Treatment Team are based at Monkwearmouth Hospital and are split into three work streams. These cover positive behaviour support, mental health and physical health. Each stream have a skill mix of various professionals including nurses, physiotherapy, occupational therapy, psychology, speech and language therapists and psychiatry.

There is one point of access to the service. A referral should be made once consent has been given by the patient or a best interest decision has been made. The health professional should contact IRS (Initial Response Service) on 0303 123 1145 where the call will be triaged by a call handler and signposted to the most suitable department. It may be that the person is already open to the team therefore any new issues can be picked up quickly. However new referrals are typically allocated for a consultation within a two week period. The Health Promotion team are also available to take calls if you have queries or want to establish if the referral is appropriate or if other services e.g. social care may be more suitable.

See: http://www.sunderlandactionforhealth.co.uk/wp-content/uploads/2015/06/Getting-help-from-services.pdf link to Easy Read Information leaflet about the community Treatment Team in Sunderland.

Risk Stratification

As we know all people over the age of 65 who have comorbidities and complex health needs and where hospital admissions are to be avoided can be offered an Emergency Health Care Plan via a MDT in each practice.

Currently we do not have a representative from learning disabilities services who can be called upon to provide information about people they may know who are eligible for these plans. There will be discussions soon under the Vanguard process to see how learning disabilities could be involved in this process going forward.

There is also an opportunity where a person has complex health care needs to have a health and social care plan coordinated by their GP practice.

Advocates

Autistic adults can benefit greatly from having an advocate with them when they need to see their GP or a healthcare professional. Someone who knows the adult well, and who understands any difficulties that they may have communicating why they have gone to see their GP can make the difference between a successful or an unsuccessful appointment.

Some individuals do not have a good understanding about their autism and how it impacts on them. They find it difficult to explain why they are actually attending an appointment.

Sometimes an adult will need to have someone attend an appointment with them so they can listen to what the doctor or health care professional is saying. This is because when stressed or anxious the adult might not fully understand what they are being told or be able to process the conversation.

Autism in Mind (Advocacy for Autism)

Autism in Mind act as advocates for individuals with autism. We do this by supporting the individual and giving them a voice to make sure that they are communicating effectively. We support individuals to make doctors and hospital appointments. We empower individuals to find their own voice and to become self-advocates whenever possible.

Sunderland People First (Advocacy for Learning Disabilities)

Sunderland People First are unique. They are the only company in Sunderland where people with a learning disability and / or autism come together and speak up around issues which impact on their lives and that of the wider community.

They promote equality & diversity and advancement of health and community development on behalf of people with learning disabilities and / or autism in Sunderland, by obtaining and representing their views, campaigning for policy and service developments and leading and influencing key learning disabilities strategic partnerships.

Formal Advocacy – Total Voice Sunderland

Total Voice Sunderland is a service delivered in partnership between Mental Health Matters (MHM) and Voiceability. They work across the city of Sunderland, offering a range of advocacy for people living in the area. They also provide:

Community Advocacy

We represent and support people who live in Sunderland, particularly people aged 18 years and over who have:

- Learning disabilities;
- Autism spectrum conditions;
- Physical disabilities, including sensory impairment;
- Mental health needs;
- Substance misuse issues;
- Older People aged 65 years and over;
- Any Adult at Risk who requires support through the safeguarding adult's process.

Independent Mental Health Advocacy Service (IMHA)

Qualifying patients detained under the Mental Health Act are entitled to an independent advocate. An IMHA will represent you and support you with:

- Understanding and exercising your rights under the Mental Health Act;
- Being fully involved in your care planning;
- Your access to Mental Health Review Tribunals, preparing for them and understanding decisions made;
- Your access to other support or services;
- Discussing appropriate aftercare;
- How to raise concerns about your experience / care.

Independent Mental Capacity Advocacy (IMCA)

IMCAs support and represent people who lack mental capacity.

When is an IMCA needed?

IMCA is needed when decisions are needed to be made around serious medical treatment, accommodation, deprivation of liberty and in some circumstances safeguarding proceedings and care reviews.

Deprivation of Liberty Safeguards and Relevant Person's Representation

A referral can be made by a supervisory body. You will need to check the local authority guidelines about when you can refer for care reviews and safeguarding proceedings. If you are the decision maker, you will need to confirm whether family and friends are 'appropriate' to consult

Litigation Friend

Referrals can be made for a litigation friend by the Local Authority. They can also be appointed by the court.

What the Advocate will do?

- Listen to you and treat you with respect;
- Be on your side;
- Support you to tell people what you think;
- Make sure you are fully involved in decisions being made about you;
- Help you to find out information, so you can make your own decision;
- Help you explore and understand your rights.

Who can make a referral?

They are happy to take referrals from anybody who wants to use their service, professionals, friends or family members and other voluntary organisations. You can contact then to discuss any situation and they will discuss the best way forward for the person involved.

Contact Details:

Address: 1d North Sands Business Centre, Liberty Way, Sunderland, SR6 0QA

Telephone: (0191) 510 5051

Website: http://www.mentalhealthmatters.com/service/sunderland-imha-service/

The Health Promotion Team

The service is aimed at meeting the health needs of adults with a learning disability, who access day services and who live in Sunderland. The scope of the team was widened to include anyone with a learning disability, not just those in day care.

The health promotion team will provide support to the service user and their carer, to ensure health and wellbeing outcomes are achieved. This will be achieved by working with families and the service users to develop care plans/ health action plans. Ensuring theses are linked to GP annual health checks and the team will support access to primary and secondary care services as required.

They will give advice on health related issues and provide health promotion and education with day service/ care provider staff. This will include reviewing and monitoring health care plans, and making referrals as required into the Community Team as required.

The team will be closely linked to Acute and Primary Care liaison service and GP’s. They will be able to support desensitisation/ support prior and during appointments etc.

The Learning Disability Community Treatment Team purpose is to support mainstream health services, by providing specialist advice/consultation and/or education. As part of the health promotion service this will be provided jointly.

Primary care can contact any of the health promoters directly to discuss potential referrals. Their contact details have been provided earlier in the document.

7) Primary Care Steering Group

Aim & Objectives

The primary care steering group was established to oversee the development and to have ownership of the learning disability & autism primary care programme documentation. The group agreed to be representatives of their localities and be the link between practices and this group around learning disabilities and autism.

Following the launch of this documentation in March 2017, the group have agreed to remain together with a different focus. Throughout the development of this documentation the group have pulled together a Primary Care Action Plan which they want to work with practices to deliver to improve the quality of care for patients with learning disabilities and or autism.

This group is responsible to the Sunderland Local Implementation Group (LIG), the LIG reports directly into the North East & Cumbria Transforming Care Board and the CCGs MH Programme Board. The future steering group will be chaired by Angela Lockyear the Clinical Lead for Learning Disabilities and Autism.

Membership Moving Forward

Alex Harrison – HCA in the East Locality;

Angela Lockyear – Future Chair of Group, Clinical Lead & Practice Nurse, North Locality;

Ashley Murphy – Primary Care Facilitator;

Chrissie Todd – West Locality Practice Manager & Practice Manager;

Gloria Middleton – Business Manager, Coalfields Locality;

Helen Brace – East Locality Practice Nurse & Practice Nurse;

Jackie Russell – Washington Locality Practice Manager & Practice Manager;

Kay Clark – Practice Manager, Washington Locality;

Lesley Blakeston – West Locality Practice Manager & Practice Manager;

Linda Reiling – Joint Commissioning Manager (Mental Health, Learning Disabilities & Autism) Sunderland Dementia Lead;

Wendy Page – Practice Manager.

8) Awareness & Training

TITO Training

The training will be based around what is your role (whether you are a clinician, Manager or administrator) within primary care for your patients who have a learning disability and or autism, the training will look at what is a learning disability, what is autism, where there are similarities and what are the differences, what is a reasonable adjustment, how to make those reasonable adjustments and making personalised reasonable adjustments.

- 8th March 2017, the **Launch** is to enable us to hit the agreed timescales within the CCG Transformational Plans**;**
- 10th May 2017, GP / PN / NP Learning Disability & Autism Primary Care **Training** session;
- 14th June 2017, HCAs Learning Disability & Autism Primary Care **Training** session;
- 19th July 2017, Practice Managers and Administration Learning Disability & Autism Primary Care **Training** session.

As CQC expects practices to illustrate how they deal with vulnerable groups, practices can note that this training will help demonstrate that.

Locality Training

As it's not feasible for all practice staff to attend the TITO it has been agreed that if localities would like to receive the learning disability and autism training delivered by Ashley Murphy, Primary Care Facilitator and Carole Rutherford, Director of Services for Autism in Mind they can request for this to take place within localities. Please contact Linda Reiling if this is of interest. All training will be recorded so practices will be able to access a copy of this to show in house.

Bespoke Practice Training

Bespoke practice training is available for those practices that require this upon request and pending requirements and capacity.

Resource Websites

All current information in relation to the health of people with a learning disability can be found on the Sunderland Action for Health website. It is a website that provides information to the person, their families and all health and social care professionals. It has been divided up into sections to help make it easier to navigate. There is a dedicated section for primary care, secondary care and specialist services. There is also a section for professionals only. This website is in constant development and new resources are added frequently.

This is also used as a forum to share events and news stories about people with a learning disability. Most importantly the website is where the current downloadable health action plans are kept that replaced the yellow books. The website needs to be open during an annual health check so if any areas of health are identified as needing improvement the health action plan can be selected, printed and given to the patient.

9) Local Requirements / Resources

CCG Learning Disability & Autism Management Lead – Linda Reiling is the lead in Sunderland. The Transforming Care Agenda comes under her remit alongside learning disabilities and autism.

CCG Learning Disability & Autism Clinical Lead – Angela Lockyear is the Clinical Lead in Sunderland. The management lead and clinical lead work closely together to deliver the CCGs objectives around learning disabilities and autism. The Clinical Lead role will have particular focus within primary care.

Primary Care Facilitators - There are two primary care facilitators in Sunderland who are employed by NTW but seconded to work predominantly with the CCG to bridge the gap between specialist services and primary care.

Their email addresses are as follows:
ashley.murphy@ntw.nhs.uk
jennifer.burn@ntw.nhs.uk

The main dimensions to their roles are as follows:

- To provide a highly specialist consultative resource to City Hospitals Sunderland, and Primary Care Teams working in the City of Sunderland with regards to meeting the health needs of people with a learning disability;
- To lead the implementation of Health Action Plans in partnership with people with a learning disability, their families and carers, other professionals and agencies, to ensure access to appropriate health screening and to promote optimum good health;
- To collaborate with colleagues in primary and secondary health care services to develop appropriate care pathways for people with a learning disability;
- To support and advise on the development of accessible information on specific health needs for people with a learning disability;
- To develop and undertake Health Promotional work in collaboration with people with a learning disability and their families and carers.

About Autism In Mind (AIM)

Aim is commissioned by NHS Sunderland Clinical Commissioning Group to provide low level preventative support. They are a solution focused service that works with individuals and families to enable them to live as independently as possible, with the knowledge that if they need any further support, it is available.

They work with individuals and families helping them to resolve any issues or problems they have. They endeavour to stop things from becoming worse and reaching crisis point. AIM supports individuals in many different ways:

- Providing a link to other services;
- Making and attending appointments;
- Support during benefit assessments;
- Offering personal profiling for individuals;
- Self-awareness and understanding sessions;
- Supporting housing or accommodation issues.

They also offer an adult’s autism outreach service to individuals on the autistic spectrum who are socially isolated and are unable to attend drop-in sessions, but who are in need of support.

About Sunderland People First

Sunderland People First is a self-advocacy Community Interest Company for people with learning disabilities and autism.

Self-advocacy exists to provide some of the most vulnerable people in society with a voice, cost-effective means of support, to protect people’s rights as citizens, encouraging self-responsibility and promoting independence, to live fulfilling lives. They promote the rights, equality, diversity and responsibilities of people with learning disabilities and autism.

Sunderland People First currently employ four staff who support ten advocates with learning disabilities and or autism, who drive forward their work, and provide a representative voice for people with learning disabilities and autism, giving people the tools to make informed decisions about things which affect them.

They work with partners to improve health and social care in areas which matter to people with learning disabilities and/or autism. Promote inclusion for people with learning disabilities and/or autism and their families in their communities.

10) Regional Requirements

Transformation Agenda

After the publication of Building the Right Support, the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS) supported the creation of 48 Transforming Care Partnerships (TCPs).

Each of those 48 TCPs have been working on their plans to change services in a way that will make a real difference to the lives of children, young people and adults with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition.

Plans include things like improving community services so that people can live near their family and friends, and making sure that the right staff with the right skills are in place to support and care for people with a learning disability and/or autism.

Each of the local plans will be 'living' documents', continuing to be developed in partnership with people with a learning disability and/or autism and their families and carers, as well as charities and other groups, to evidence a real shift in the balance of power and to make sure the plans meet local needs and continue to drive up the quality of care.

Cumbria and North East Transforming Care Partnership's (TCP) plans include investing in services for people with attention deficit hyperactivity disorder and autism, advocacy services and carers' support.

The TCP is also testing a new kind of housing scheme which has been developed by the NHS and other care providers to improve the quality of support for people and to prevent hospital admissions and will give staff the skills needed so that they can deliver these new types of care.

The full plan and an easy read version of the plan is available on: http://www.necsu.nhs.uk/necfasttrack

Cumbria and North East TCP is made up of the following Clinical Commissioning Groups and Local Authorities:

Clinical Commissioning Groups

- Cumbria CCG;
- Darlington CCG;
- Durham Dales, Easington and Sedgefield CCG;
- Hartlepool and Stockton-on-Tees CCG;
- North Durham CCG;
- Newcastle Gateshead CCG;
- North Tyneside CCG;
- Northumberland CCG;
- South Tees CCG;
- South Tyneside CCG;
- Sunderland CCG.

Local Authorities

- Cumbria County Council;
- Darlington Borough Council;
- Durham County Council;
- Gateshead Metropolitan Borough Council;
- Hartlepool Borough Council;
- North Tyneside Council;
- Northumberland County Council;
- South Tyneside Metropolitan Borough Council;
- Sunderland City Council;
- Redcar and Cleveland Borough Council;
- Stockton-on-Tees Borough Council;
- Newcastle upon Tyne Council;
- Middlesbrough Council;

The Senior Responsible Officer (SRO) for North East & Cumbria Transforming Care is: David Hambleton.

Networks and Meetings

There are a number of networks and meetings which are linked and part of the transforming care agenda structure. For further information you can view the website: http://www.necchangingcare.org.uk/

11) Other Requirements

Learning Disability QoF

The Quality and Outcomes Framework (QOF) is a voluntary annual reward and incentive programme for all GP surgeries in England, detailing practice achievement results. It is not about performance management but resourcing and then rewarding good practice.

DES (Direct Enhanced Service)

All practices are expected to provide essential and additional services they are contracted to provide to all their patients. An enhanced service specification outlines the more specialised services to be provided. The specification is designed to cover enhanced aspects of clinical care of the patient with severe learning difficulties, which go beyond the scope of essential services. No part of the specification by commission, omission or implication defines or redefines essential or additional services.

Learning Disability & Autism CCG QP

Sunderland CCG are working towards developing QP which learning disabilities and autism are currently part of. The practices have been part of this process and we are awaiting the outcome as to whether this will proceed.

Five Year Forward View Mental Health (FYFV)

The Five Year Forward View Mental Health report is an independent report of the Mental Health Taskforce which sets out the start of a ten-year journey for transformation. Within this report they have made a set of recommendations for the six NHS arm's length bodies to achieve the ambition of parity of esteem between mental and physical health for children, young people, adults and older people.

They also set out recommendations where wider action is needed based on feedback they received stating that as well as access to good quality mental health care wherever patients are seen in the NHS, their main ambition for patients was to have a decent place to live, a job or good quality relationships in their local communities. The report acknowledges that making this happen will require a cross government approach.

They have placed a particular focus on tackling inequalities. Mental health problems disproportionately affect people living in poverty, those who are unemployed and who already face discrimination. For many, especially black, asian and minority ethnic people, their first experience of mental health care comes when they are detained under the Mental Health Act, often with police involvement, followed by a long stay in hospital. Tackling inequalities at a locality and national level will address this.

Policy Context FYFV

There has been a transformation in mental health over the last 50 years which progressed from the growth of community based mental health services in the 1990's when the Care Programme Approach was developed. In 1999 the National Service Framework for Mental Health was launched and was then followed by the NHS Plan in 2000 which set targets and provided funding to make the Framework a reality.

A National Service Framework for Children, Young People and Maternity Services was launched in 2004 and in 2011 the Coalition Government published a mental health strategy which set six objectives. Over the last five years, public attitudes towards mental health have improved, in part due to the Time to Change campaign; this has increased awareness and has heightened understanding of an urgent need to act on improving the experience of people with mental health problems.

The focus is now to re-energise and improve mental health care across the NHS and in this context, NHS England and the Department of Health published Future in Mind in 2015, which articulated a clear consensus about the way in which we can make it easier for children and young people to access high quality mental health care when they need it. This strategy builds on these foundations.

Priority Actions for the NHS by 2020/21

All too often people with mental health problems still experience stigma and discrimination, many people struggle to get the right help at the right time and evidence-based care is significantly underfunded. The report notes that the human cost is unacceptable and the financial cost to government and society is unsustainable.

Leaders across the system must take decisive steps to break down barriers in the way services are provided to reshape where care is delivered, increase access to the right care at the right time, drive down variations in the quality of care, and improve outcomes. Their ambition is to deliver rapid improvements in outcomes by 2020/21 through ensuring that 1 million more people with mental health problems are accessing high quality care.

The report sets out 3 Priority actions for the NHS by 2020/21:

1) A 7 day NHS – right care, right time, right quality:

2) An integrated mental and physical health approach:

3) Promoting good mental health and preventing poor mental health – helping people lead better lives as equal citizens:

Please see **Appendix 18** the Five Year Forward View for Mental Health document.

Westminster Commission into Autism Report

Following a seven – month inquiry and consultation of over 900 people, the Westminster Commission on Autism launched a report which calls for improved access to healthcare for all autistic people.

‘It is critical to improve access to healthcare for autistic people of all ages. This population have increased health risks and reduced life expectancy, yet face multiple obstacles to accessing the same healthcare that other population groups enjoy’. For full report see **Appendix 19.**

12)Links / Resources / Contacts

CCG Management Lead
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CCG Clinical Lead
Angela Lockyear
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Primary Care Facilitators
Ashley Murphy & Jennifer Burn
Email: ashley.murphy@ntw.nhs.uk
Email: jennifer.burn@ntw.nhs.uk

Autism in Mind
Phone - 0191 5672514
E-mail - info@autisminmind.com
Website - www.autisminmind.com

Sunderland People First
Phone – (0191) 521 4123
To send an Email access – http://sunderlandpeoplefirst.com/contact-us/
Website – www.sunderlandpeoplefirst.com

- RCGP LD web resource page http://www.rcgp.org.uk/learningdisabilities
- RCGP Autism web resource page http://www.rcgp.org.uk/ASD
- Sunderland Action for Health page www.sunderlandactionforhealth.co.uk
- Learning Disabilities Best Interest Pathway www.rcgp.org.uk/learningdisabilities/~/media/Files/CIRC/Learning...
- Mental Health Capacity Act Toolkit www.rcgp.org.uk/.../CIRC-Mental-Capacity-Act-Toolkit-2011.ashx
- Five Year Forward Mental Health https://www.england.nhs.uk/.../Mental-Health-Taskforce-FYFV-final.pdf
- Reducing Premature Mortality https://www.gov.uk/government/uploads/system/uploads/attachment...
- Autism Patient Charter www.autism-alliance.org.uk/upload/pdf_files/1432894276_Autism...
- Care Passport (Health Action Plan toolkit) http://www.sunderlandactionforhealth.co.uk/action-plans/introduction-to-our-health-action-plan-toolkit/
- Access to Housing www.sunderland.gov.uk/CHttpHandler.ashx?id=7754&p=0&ftype=PDF
- Face scale http://wongbakerfaces.org/

13)Reference List

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- NHS Choices (no date) Profound and Multiple Learning Disability. http://www.nhs.uk/livewell/childrenwithalearningdisability/pages/whatislearningdisability.aspx Last accessed Jan 2017.
- Bill Nason Master of Science, Psychologist, specialising in autism and severe challenging behaviour.
- How People with Learning Disabilities Die. Improving Health and Lives. 2010.
- Winterbourne Medicines programme. NHS Improving Quality report. 2015
- NICE (2015) Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges - guidance (NG11) National Institute for Health and Care Excellence. www.nice.org.uk
- Royal College of Psychiatry (RCPsych). (2016) Psychotropic drug prescribing for people with intellectual disability, mental health problems and/or behaviour that challenges: practice guidance. FR/ID/09
- NHS England (July 2015) The use of medicines in people with learning disabilities. Letter signed by Dominic Slowie and Keith Ridge. Public Gateway Reference 03689
- Care Quality Commission (Sept 2015) Brief guide: psychoactive medicines (Learning Disabilities)

14) Appendices

Appendix 1 - Autism Strategy
Appendix 2 - Think Autism
Appendix 3 - IHAL Report
Appendix 4 - Annual Health Check Audit Action Plan
Appendix 5 - The 5 principles
Appendix 6 - The Flu Protocol
Appendix 7 - The Flu Plan
Appendix 8 - Hidden Voices Report
Appendix 9 - Bowel Screening Project Report
Appendix 10 - EHEF Presentation
Appendix 11 - NICE (2005) Challenging Behaviour Report
Appendix 12 - Stopping Over Medication Presentation (Jan 2017 - TITO)
Appendix 13 - The use of medicines in people with learning disabilities - Letter
Appendix 14 - Brief Guide to Psychotropic Medication
Appendix 15 - Mortality Review Communication Strategy
Appendix 16 - TITO presentation re hearing loss and complex needs.
Appendix 17 - Referral form for Community Dentistry
Appendix 18 - Five Year Forward View for Mental Health
Appendix 19 - Westminster Report

Department
of Health

Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy

March 2015

Title: Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy

Author: Social Care, Local Government and Care Partnerships, Mental Health and Disability and Dementia

Cost code: 11165

Document purpose:

Guidance

Publication date:

March 2015

Target audience:

Chairs and Chief Executives of Local Authorities, CCGs, NHS Trusts, NHS England, Care Trusts, Foundation Trusts. Health and Wellbeing Boards, Directors of Public Health, Medical Directors, Directors of NHS England Nursing, Local Authority Directors of Adult Social Services, NHS Trust Board Chairs, Special HA CEs, Local Authority Directors of Children’s Services, Royal Colleges, Third sector organisations, Health Education England, Professional bodies representing staff, especially Nursing, Physiotherapists, Social Workers, General Practitioners, Psychiatrists, Psychologists, Allied Health Professionals, Special Education Consortium, Preparing for Adulthood, the Association of Colleges and the Association of School and College Leaders, Prison Governors and Directors, Community Rehabilitation Companies and the National Probation Service.

Contact details:

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Published to gov.uk, in PDF format only.

www.gov.uk/dh

Department
of Health

Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy

Prepared by the Department of Health

Contents

Ministerial foreword

The Autism Act 2009[1] remains the first and so far the only condition-specific legislation of its type in England. This demonstrates the importance Parliament has attached to ensuring that the needs of people with autism are met.

The original Adult Autism Strategy *Fulfilling and Rewarding Lives*[2] was published in 2010. In April 2014 this was updated by *Think Autism*.[3] This statutory guidance supports the strategy and its update, *Think Autism*, by giving guidance to local authorities and NHS bodies about the exercise, respectively, of their social care and health service functions (for the purpose of securing the implementation of the strategy and its update). The guidance builds on progress made over the last five years and sets out the expectations for local areas so they can continue to develop services and support in ways that reflect the assessed needs and priorities of their communities to secure implementation of the strategy.

Local Authorities and the NHS need to work in collaboration with local partners to take forward the key priorities in *Think Autism*. Crucially, at its core, people with autism need to have access to a clear pathway to diagnosis and know that this pathway is aligned with care and support assessments, and that there is post-diagnostic support available even if the person does not meet social care support criteria. Commissioning decisions need to be based on knowledge and awareness of autism, the needs of the local population, and informed by people with autism and their families.

The wider legislative changes since 2010 will also enable local services to support people with autism and their families better, and they are also outlined in this statutory guidance. The Children and Families Act 2014[4] will help to support young people in preparing for adulthood. The Care Act 2014[5] places a strong emphasis on preventing and delaying needs for care and support, making sure that there is appropriate information and advice for people, support for carers, and promoting integration between social care and health care services. It also places a duty on local authorities to promote a person's well-being when carrying out any of their care and support functions in respect of that person.

Autism should also not be seen as an add-on to services and with over half a million people on the autism spectrum in England, mainstream services will already be seeing or in contact with many people who have autism. By encouraging more innovation in the way services are delivered and through services making more reasonable adjustments, individuals can go to their local council office, GP or hospital feeling confident that those services are aware of their autism and knowing that adjustments can be made for them. Training and awareness of autism are key here.

Those who have followed the Adult Autism Strategy over the past five years will recognise that, as our approaches mature, our ambition has grown. *Think Autism* moved the original vision of the strategy on, including an increased focus on areas such as criminal justice and employment. It is only right that the statutory guidance should do likewise.

Local authorities and the NHS have made a lot of progress in the ways that adults with autism are supported. The challenge is now to build on this progress, ensuring that this guidance is followed to make sure that we improve the lives of hundreds of thousands of people with autism and their families. Also included is good practice and suggested actions that build on the statutory requirements. I know that you will join me in taking up this challenge, and this updated guidance will help local authorities and the NHS reach our shared vision for all adults with autism to live fulfilling and rewarding lives within a society that accepts and understands them.

Norman Lamb
Minister for Care and Support

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[1] Autism Act 2009 http://www.legislation.gov.uk/ukpga/2009/15/contents

[2] "Fulfilling and rewarding lives" The strategy for adults with autism in England (2010) http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369

[3] "Think Autism. Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update" (2014) https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy

[4] Children and Families Act 2014 http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted

[5] Care Act 2014 http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

Status of this guidance

1. This guidance is statutory guidance issued under section 2 of the Autism Act 2009 (the Act). It is issued to local authorities, NHS bodies and NHS Foundation Trusts and replaces the 2010 statutory guidance. It relates to England only.

2. An NHS body, under the Act and in this guidance, means the National Health Service Commissioning Board (referred to in the remainder of this guidance by its operational name, NHS England), a clinical commissioning group, an NHS Trust all or most of whose hospitals, establishments and facilities are in England and a Special Health Authority performing functions only or mainly in respect of England.

3. As set out in section 3 of the Act, it is to be treated as though it were guidance issued under section 7 of the Local Authority Social Services Act 1970[6] (LASS Act). This means that local authorities must "follow the path charted by the guidance, with liberty to deviate from it where the authority judges on admissible grounds that there is good reason to do so, but without freedom to take a substantially different course."

4. Though the LASS Act does not directly apply to NHS bodies, section 3(2) of the Act makes it clear that for the purposes of this guidance "an NHS body is to be treated as if it were a local authority within the meaning of the LASS Act". The Act also specifies that the functions of an NHS body concerned with the provision of relevant services (namely health services provided for the purposes of the health service) are to be treated as if they were social services functions within the meaning of the LASS Act.

5. Local authorities and NHS bodies must not only take account of this guidance, but also follow the relevant sections or provide a good reason why they are not doing so (one example might be because they can prove they are providing an equivalent or better alternative). If they do not follow the guidance and cannot provide a good reason, they may be liable to judicial review or action by the Secretary of State.

6. The definition of NHS body in the Act does not include NHS Foundation Trusts. However, this guidance does include Foundation Trusts, and throughout, it is stated clearly what the responsibilities of local authorities, NHS bodies and NHS Foundation Trusts are. NHS Foundation Trusts will be expected to follow the guidance as it applies to them (unless there is good reason for not doing so), such as when planning and providing services for adults with autism, for example, in commissioning diagnostic services.

7. The guidance also includes good practice and suggested actions that build on the statutory requirements and existing guidance.

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[6] Local Authority Social Services Act 1970 http://www.legislation.gov.uk/ukpga/1970/42/contents

About this guidance

1. The purpose of this guidance is to secure the implementation of the Adult Autism Strategy "*Fulfilling and Rewarding Lives: The Strategy for Adults with Autism in England*" 2010 as updated by *Think Autism* (2014) by giving guidance to Local Authorities, NHS Foundation Trusts and NHS bodies.

2. The guidance focuses on the areas which section 2 of the Autism Act 2009[7] requires to be addressed, in each case identifying what Local Authorities, Foundation Trusts and NHS bodies are already under a duty to do under legislation, what they are expected to do under other existing guidance, and what they should do under this guidance. Local Authorities, NHS bodies and Foundation Trusts should already be doing much of what is expected of them in complying with this guidance as they should have followed the 2010 statutory guidance (which this guidance builds on and replaces).

What has changed since 2010?

3. There have been major changes to many parts of the health and social care system, services and legislation since the Act and the 2010 Autism Strategy. These changes are summarised in Appendix A.

4. We have also, following our review of the 2010 Autism Strategy, refreshed it with *Think Autism* published in April 2014. This set out an updated programme of action to deliver the aims of the Act and is summarised in Appendix B. It places greater emphasis on involvement and awareness within the local community and on ways to look differently at support and engagement. *Think Autism* therefore builds on the 2010 Autism Strategy rather than replaces it, and the two should be read together.

5. In addition, we continue to expect local authorities, NHS bodies and Foundation Trusts in every local area to remain committed to the 2010 Autism Strategy.

6. Additionally, as well as reflecting the key legislation and health and social care reforms since 2010, the guidance puts greater emphasis on involvement and awareness within the local community and on ways to look to improve the way health and social care services identify the needs of adults with

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[7] Section 2 of the Autism Act requires that the guidance must, in particular, include guidance about- (a) the provision of relevant services(namely, as regards NHS bodies, health services provided for the purposes of the health service and, as regards local authority, services provided in exercise of their social services functions under the LASS Act) for the purpose of diagnosing autistic spectrum conditions in adults; (b) the identification of adults with such conditions; (c) the assessment of the needs of adults with such conditions for relevant services; (d) planning in relation to the provision of relevant services to persons with autistic spectrum conditions as they move from being children to adults; (e) other planning in relation to the provision of relevant services to adults with autistic spectrum conditions; (f) the training of staff who provide relevant services to adults with such conditions; and (g) local arrangements for leadership in relation to the provision of relevant services to adults with such conditions.

autism. It also aim to ensure identified needs are met more effectively to improve the health and well-being of adults with autism.

7. These are both important points with regard to fulfilling the new challenges people with autism have set us in *Think Autism*. We remain committed to our future vision that:

> *"All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them, they can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents".*

Terminology

8. Throughout the guidance, as in the strategy, we use the term "autism" as an umbrella term for all autistic spectrum conditions, including Asperger Syndrome. Many people with autism also have related hidden impairments such as attention deficit hyperactivity disorder, dyspraxia, dyslexia, dyscalculia and language impairments as well as associated mental health conditions and linked impairments that may not be obvious to other people.

Monitoring Local Authorities, NHS Foundation Trusts and NHS bodies progress against the requirements in the guidance

How will the Department of Health check progress of local communities'?

1. The Department of Health intends to continue to support Health and Wellbeing Boards through the local area autism self-evaluation exercise on an annual basis and to make the responses publicly available. The self-evaluation exercise will help demonstrate progress being made in implementing the Adult Autism Strategy, and highlight examples of good practice around the country.

2. There have been two self-assessment exercises undertaken by local authorities and their partners. A baseline assessment was carried out in 2011,[8] with a follow up assessment completed in 2013.[9]

3. A further self-assessment exercise is currently underway this year for 2014/15. This will enable adults with autism, their families and carers, and autism representative groups to hold services to account and assess whether changes are taking place. It will also allow the Department to compare progress across different areas identify areas where progress is still to be made and allow areas to compare performance with peers and neighbours.

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[8] Autism Self-Assessment 2011 – https://www.improvinghealthandlives.org.uk/publications/1157/Autism_Self_Assessment_2011

[9] Autism self-assessment framework 2013 – http://www.improvinghealthandlives.org.uk/projects/autism2013

Understanding this guidance

1. Where the guidance says local authorities, NHS bodies and Foundation Trusts “must” it refers to legal duties imposed upon these bodies by the Autism Act 2009 or other Acts of Parliament e.g. the Care Act 2014, and the Children and Families Act 2014 (or secondary legislation made under such Acts).

2. Where the guidance says local authorities/NHS bodies/Foundation Trusts “should” it refers to statements of policy or information with regard to the way in which Local Authorities (and in particular their Social Services Directors), NHS bodies and Foundation Trusts should exercise their functions with a view to securing the implementation of the autism strategy.

3. Local Authorities (and in particular their Social Services Directors), NHS bodies and Foundation Trusts may depart from this but only if they can demonstrate a good reason for doing so. Lack of sufficient resource would not necessarily constitute a good reason. These statements are intended to reflect current practice in many localities since the Autism Act 2009 and the first published Adult Autism statutory guidance (December 2010) or are drawn from evidence bases, for example, from the autism self-evaluation exercise, or available qualitative research and information gathered during review and refresh of the Autism Strategy in 2013/14.

What the coloured boxes mean

4. To help navigate through the sections three different coloured boxes have been used to guide you about what your responsibilities are under the statutory guidance.

🟧 Local Authorities

🟩 NHS Bodies

🟥 Local Authorities and NHS Bodies and NHS Foundation Trusts

Who must have regard to this guidance?

1. This guidance is for:

- Local Authorities in relation to the exercise of their social services functions; and
- The following bodies in relation to the exercise of their functions concerned with the provision of health services for the purpose of the health service in England: NHS Foundation Trusts, NHS Trusts all or most of whose hospitals establishments and facilities are in England, the NHS Commissioning Board (referred to in the remainder of this guidance by its operational name, NHS England), Clinical Commissioning Groups (CCGs) and Special Health Authorities performing functions only or mainly in respect of England.

2. The above bodies should ensure that this guidance is also followed by other organisations that deliver services under contract for them, such as those contracted to provide accommodation in a care home or day care on behalf of a local authority etc.

3. Independent sector providers (including both for profit and not for profit providers) who are providing services for the NHS via commissioning arrangements with the Board or CCGs or for local authorities (exercising their social services functions) via commissioning arrangements are required to follow the guidance if that requirement is included in those commissioning arrangements as it would be expected to be. So, on that basis, wherever guidance is included that refers to NHS bodies and/or local authority delivered services then independent sector providers should ensure that they follow this guidance.

4. We recommend that other providers of public services, such as providers of services to support people into employment, police, probation and the criminal justice system look to follow the guidance to help improve the delivery of the services they provide to adults with autism: for example ensuring that staff who provide services to adults with autism have received autism awareness training would clearly be of value across all public services. This should lead to better outcomes for people with autism and make best use of public resources.

5. It is also good practice for any provider who is delivering care which is self-funded, for example by the individual, their family or insurance, to follow the guidance.

6. The guidance may also be of interest to readers in Scotland, Wales and Northern Ireland (who have their own legislation and strategies).

1. Training of staff who provide services to adults with autism

1.1. Improving training around autism is at the heart of the autism strategy for all public service staff but particularly for those working in health and social care. This includes not only general autism awareness training, but also different levels of specialist training for staff in a range of roles, where this is needed to fulfil their responsibilities and for those who wish to develop their knowledge of autism.

1.2. When professionals do understand autism, the positive impact on the lives of adults with autism can be immense. Health and social care professionals must be able to communicate effectively with people with autism if they are to be able to manage their own care and exercise genuine choice and control. The 2010 statutory guidance for local authorities and the NHS made it clear that basic autism training should be available to all staff working in health and social care. This remains a key requirement of this updated statutory guidance.

1.3. From April 2015, the Care and Support (Assessment) Regulations 2014[10] will require local authorities to ensure that a person undertaking an assessment of an adult's care and support needs has suitable skills, knowledge and competence in the assessment they are undertaking, and is appropriately trained, and require local authorities, when carrying out an assessment, to consult a person who has expertise in relation to the condition or other circumstances of the individual whose needs are being assessed where it considers the needs of that individual require it to do so.

1.4. In line with the 2010 statutory guidance, local authorities should be providing general autism awareness to all frontline staff in contact with adults with autism, so that staff are able to identify potential signs of autism and understand how to make reasonable adjustments in their behaviour and communication. In addition to this, local authorities are expected to have made good progress on developing and providing specialist training for those in roles that have a direct impact on and make decisions about the lives of adults with autism, including those conducting needs assessments. This expectation remains central to this updated statutory guidance.

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[10] Care and Support (Assessment) Regulations 2014 http://www.legislation.gov.uk/uksi/2014/2827/pdfs/uksi_20142827_en.pdf

Local Authority, NHS bodies and NHS Foundation Trusts should:

- Ensure autism awareness training is included within general equality and diversity training programmes for all staff working in health and care;
- Ensure that all autism awareness training enables staff to identify potential signs of autism and understand how to make reasonable adjustments in their behaviour, communication and services for people who have a diagnosis of autism or who display these characteristics;
- Ensure that there is a comprehensive range of local autism training that meets National Institute for Health and Care Clinical Excellence (NICE) guidelines for those staff who are likely to have contact with adults with autism;
- Ensure those in posts whose career pathways are highly likely to include working with adults with autism (for example, personal assistants, occupational therapists, residential care workers, frontline health staff including all GPs and psychiatrists) have demonstrable knowledge and skills to:
- Use appropriate communication skills when supporting a person with autism;
    - Support families and friends and make best use of their expert knowledge of the person;
    - Recognise when a person with autism is experiencing stress and anxiety and support them with this;
    - Recognise sensory needs and differences of a person with autism and support them with this;
    - Support the development of social interaction skills;
    - Provide support with transitions and significant life events;
    - Understand the issues which arise from co-occurrence of mental ill health and autism;
    - Support people with autism to gain and maintain employment (where appropriate);
- Ensure those in posts who have a direct impact on and make decisions about the lives of adults with autism (including, for example, psychiatrists, those conducting needs assessments) also have a demonstrable knowledge and skills in the areas listed above as well as a good understanding of:
    - How autism may present across lifespan and levels of ability, and are defined and diagnosed, and the relevant pathways and screening tools;
    - The common difficulties faced by individuals on the spectrum and their families/ carers, including social and economic hardship;
    - Developmental trajectory of autism;
    - The impact of autism on personal, social, educational and occupational functioning, and interaction with the social and physical environment;

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  - Current good practice guidelines (e.g. NICE Quality Standard)[11] and local diagnostic and care pathways;
  - Current good practice guidance with respect to an individual with autism's capacity to assess risk;
  - Available guidance for good practice in post-diagnostic support and intervention.
- Ensure that both general awareness and specialist autism training is provided on an ongoing basis and that new staff or staff whose roles change are given the opportunity to update their autism training and knowledge;
- Recognise that women with autism may be missed and misdiagnosed as they may be better able to mask their social difficulties. There can also be a perception that autism is something that men have and this can impact on women being referred for diagnosis. Improved awareness and training should help overcome this;
- Involve adults with autism, their families and carers and autism representative groups when commissioning or planning training. This may be in terms of inviting them to comment on or contribute to training materials, or asking them to talk to staff about autism and how it affects them, or to provide or deliver the training, for example they could help put together a multi-agency plan with regard to autism training for staff.

Good practice for local authorities, NHS bodies and NHS Foundation Trusts would be to maintain adequate staffing levels and build on the skill set of staff who are suitably trained, to ensure continuity of service.

NHS bodies and NHS Foundation Trusts should:

- Ensure they are involved in the development of local workforce planning, and GPs and primary care practitioners are engaged in the training agenda in relation to autism.

Local Authorities must:

- Ensure that any person carrying out a needs assessment under the Care Act 2014 has the skills, knowledge and competence to carry out the assessment in question and is appropriately trained. Where the assessor does not have experience in the condition, the local authority must ensure that a person with that expertise is consulted.

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[11] NICE Quality Standard on autism (2014) http://www.nice.org.uk/guidance/qs51

Additional information on good practice in delivering training effectively

1.5. As the 2010 strategy and guidance made clear, initial autism awareness training can be delivered as part of existing equality and diversity training or similar programmes. Local authorities, NHS bodies and NHS Foundation Trusts may also want to consider online training, DVDs etc. as well as using the DH-commissioned online resources and information about autism for those working in the health and social care sectors. To find out more go https://www.gov.uk/government/news/autism-training-resources

1.6. Skills for Care and Skills for Health with the National Autistic Society have developed resources to help enhance awareness of autism and improve skills among social care and health workers. To find out more go to https://www.skillsforcare.org.uk/skills/Autism/Autism.aspx

1.7. The Department of Health has commissioned the College of Social Work to develop a Continuing Professional Development curriculum guide on autism linked to the Professional Capability Framework and a set of learning materials for social workers. Both will be available later in 2015.

What else can help?

- There is considerable scope to share resources with other organisations locally – for example, co-commissioning a training programme or course.
- The most effective training will help staff put what they are learning in context, by reflecting the situations they work in – for example, in terms of the kinds of reasonable adjustments that can be made to their working environment.
- When identifying who requires training within an organisation, it is important to consider all staff – not just those in frontline service delivery. For example, a practice manager may have a key role to play in making adjustments to the environment to make it accessible for adults with autism; the response of a receptionist can make a big difference to whether an adult with autism makes and keeps an appointment.
- As well as budgeting for core awareness training, it will be necessary to allocate funding for more specialist autism training for certain staff – including those practitioners who have identified an interest to specialise in autism. It is not expected that each local authority, NHS body or Foundation Trust develops its own specialist training programme, but rather that applications for specialist training are considered within the training budget.
- When involving people with autism in the planning and delivery of training, it is necessary to ensure that the whole autism spectrum is covered, by means of considering differences in reasonable adjustments that may be required, and discouraging reliance on preconceptions of autism. Training should encourage staff to make appropriate adjustments for each individual with autism. Local authorities, NHS bodies and Foundation Trusts should make sure that involvement in training is meaningful for both trainees and people with autism.

2. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services

2.1. Diagnosis can be particularly important for adults who did not have their condition or sensory issues recognised as children. Their life to date may have been affected by a sense of not fitting in, of not understanding the way they respond to situations or why they find social settings difficult. They may also have been receiving learning disability or mental health services, where their autism was not recognised or supported.

2.2. While local authorities will lead commissioning for care and support services for people with autism, CCGs are expected to take the lead responsibility for commissioning of diagnostic services to identify people with autism, and work with local authorities to provide post-diagnostic support for people with autism (regardless of whether they have an accompanying learning disability, other hidden impairments or a co-occurring mental health problem).

2.3. A diagnosis represents the formal clinical confirmation of autism and the clear elimination of an alternative diagnostic explanation for an individual, based on all the available information – including patient experience, carer reports, direct observation and special interview schedules, to find out if characteristic behaviour was present during childhood and has continued to adulthood. A diagnosis of autism is therefore usually made by a specially trained health professional, working as part of a multi-disciplinary team. For adults, this is most commonly led by a psychiatrist, or by a clinical psychologist, or speech and language therapists who also has had sufficient training and clinical experience in diagnosing a wide range of other mental and behavioural disorders frequently found in people with autism.

2.4. A diagnosis can be an important step in ensuring that support takes account of how a person's autism affects them and their whole family, as well as their participation in learning, employment or other activities. Some people with suspected autism may not need further support. However, this does not mean that they should not have access to a diagnosis. For some people, simply having a diagnosis of autism confirmed can be incredibly important, and can help them avoid needing more intensive support at a later stage for example, if they hit a crisis point.

2.5. We have taken a number of actions since 2010 to support local authorities and NHS bodies and Foundation Trusts in each local authority area to develop a clear pathway to diagnosis and post-diagnosis. In every local area, the NHS is expected to have a pathway to diagnosis, just as the local authority should have a clear framework for assessing the care and support needs of adults with autism. We will continue to ask local authorities, NHS bodies and Foundation Trusts to assess their progress on developing and maintaining a pathway to diagnosis through the autism local area self-evaluation exercise.

2.6. Each local authority area should have an easily accessible autism diagnostic service, but it is not expected that a specialist diagnostic team will be located in all areas.

Key professionals such as GPs and mental health practitioners should be aware of the pathway and of how to refer to that diagnostic service.

2.7. To enable these duties to be fulfilled, local authorities, NHS bodies, and Foundation Trusts should take the following steps.

NHS bodies and NHS Foundation Trusts should:

- Provide access to services that can diagnose autism, and it's frequently associated medical and mental health conditions.

Clinical Commissioning Groups should:

- Designate a health lead responsible for developing, maintaining and promoting a diagnostic and treatment pathway.

Local Authorities informed by NHS bodies should:

- Seek to work with CCGs to ensure there is a suitably trained lead health professional to develop diagnostic and assessment services for adults with autism in their area.

Local Authorities and NHS bodies should jointly:

- Ensure the provision of an autism diagnostic pathway for adults including those who do not have a learning disability and ensuring the existence of a clear trigger from diagnostic to local authority adult services to notify individuals of their entitlement to an assessment of needs. NICE guidance and NICE Quality Standard on autism represent best practice when developing diagnostic services and related services.

Clinical Commissioning Groups and NHS England should:

- Establish, maintain and promote autism diagnostic pathways, working with partners in local authorities. This includes giving appropriate post diagnostic advice and support;
- Promote NICE best practice (e.g. where people seeking an autism diagnosis have a first appointment within 3 months of their referral) as set out in the NICE Quality Standard on autism [QS51]. GPs have an important role to play in recognising autism and knowing where to refer locally for a diagnosis and other support.

NHS England should:

- Ensure that GPs, as the gatekeepers to diagnostic services, have adequate training specifically in autism beyond general awareness training (as outlined in Section 1) and a good understanding of the whole autistic spectrum and the diagnostic pathway that has been developed in their area. This will enable adults with autism to be supported more effectively from the start of their assessment process.

Clinical Commissioning Groups and NHS England should:

NHS Bodies and NHS Foundation Trusts should:

- Contact the adult with autism and any registered carers to inform them about their right to a needs assessment (for the adult) and a carer's assessment (for the carer) if they may have such needs;
- When an adult is diagnosed with autism, the NHS body or NHS Foundation Trust providing healthcare services to the adult informs, with the individual's consent, the relevant local authority adult social services department promptly to ensure that a care and support assessment can be carried out within a reasonable time period if the individual wants such an assessment.

Local Authority, NHS bodies and NHS Foundation Trusts should:

- Ensure the prompt sharing of information between diagnostic services and adult social care services about adults diagnosed;
- Ensure people have timely formal notification of their entitlement to an assessment of needs and, where relevant, a carer's assessment.

Local Authorities should:

- Ensure that people with autism are aware of the right to access a needs assessment (for the adult) and a carer's assessment (for the carer). The process of obtaining one should align with the diagnosis process and be offered at the diagnosis stage and a referral made if needed.

Local Authorities duties under the Care Act 2014 from April 2015

2.8. Local Authorities will also be subject to the following duties from April 2015 and must carry them out in relation to adults with autism as with all other adults:

- Section 1 of the Care Act[12] – duty, in exercising its care and support functions under Part 1 of the Care Act in the case of an individual, to promote that individual's well-being;
- Section 3 of the Care Act – duty to exercise its functions with a view to ensuring the integration of care and support provision with health and health related provision where this would, in its area, promote well-being, help prevent or delay the development of care and support, or support, needs and improve the quality of such care and support;
- Section 4 of the Care Act – duty on local authorities to establish and maintain a service for providing people in its area with information and advice relating to care and support for adults and support for carers and in particular on how to access the care and support that is available;
- Section 6 of the Care Act – duty of co-operation in general, in exercising functions relating to adults with care and support needs and carers with support needs, between local authorities and other relevant bodies, such as NHS bodies in its area, other local authorities, and specified persons responsible for exercising functions in relation to social security, employment and training, probation services, prisons and the police;
- Section 7 of the Care Act – duty to co-operate with the same relevant bodies in specific cases relating to individuals with needs for care and support;
- The Care and Support (Assessment) Regulations 2014 – duty to give information about the assessment process to the individual being assessed;
- Regulation 5 of the Care and Support (Assessment) Regulations 2014[13] which requires a local authority to ensure that a person carrying out an assessment has the skills, knowledge and competence to carry out the assessment in question and is appropriately trained. Local Authorities must therefore ensure that assessors carrying out assessments of people with autism have the skills, knowledge, competence and training to carry out such assessments.

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[12] Part 1 of the Care Act 2014 – Sections 1,3,4,6 and 7 http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

[13] Regulation 5 of the Care and Support (Assessment) Regulations 2014 – http://www.legislation.gov.uk/uksi/2014/2827/pdfs/uksi_20142827_en.pdf

Local Authorities must:

- Under section 47(1) of the National Health Service and Community Care Act 1990,[14] local authorities have a duty to assess a person who may be in need of community care services. Section 9 of the Care Act 2014[15] will replace the duty in section 47(1) from April 2015 (as to which see below). This assessment may be triggered either by the individual requesting it or if the local authority believes community care services may be necessary. This duty applies to people with autism and is not dependent on them having been formally diagnosed as having autism. Such an assessment should be carried out by trained practitioners, and where there are potential signs of autism, the assessment should take account of the communication needs of adults with autism. Assessment of eligibility for care services cannot be denied on the grounds of the person's IQ.

This is particularly important for some people with autism, including those with Asperger syndrome, who may face very significant challenges in their everyday lives, despite having average or above average IQ.

The Care Act requires local authorities to conduct a needs assessment where it appears to the authority that the adult may have needs for care and support. It is vital that local authorities fulfil their duties under statute by ensuring that adults diagnosed with autism who may have care and support needs are offered an assessment.

Under the Care Act (from April 2015), local authorities must:

- Carry out a supported self-assessment of the care and support needs of an adult with autism if that is what the adult wishes (providing they have capacity to consent);
- Involve individuals (including those with autism and their carers) when carrying out certain care and support functions in respect of them, such as when conducting needs or carers assessments, preparing care and support, or support, plans (and when revising such plans);
- Where required provide access to an independent advocate to enable the individuals engagement in determining their support;
- Arrange access to an independent advocate for individuals with autism for the purpose of facilitating their involvement in the above mentioned matters. In particular where a person with Autism would have difficulty in understanding the process of assessment including retaining that information, and or would not be able to meaningfully contribute their views, wishes or feelings and there is no appropriate person who knows them to support them in fully engaging in the process;
- Identify the outcomes individuals (including those with autism) wish to achieve for their day to day lives in their needs assessments and carer's assessment.

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[14] Section 47(1) of the National Health Service and Community Care Act 1990 – http://www.legislation.gov.uk/ukpga/1990/19/section/47

[15] Section 9 of the Care Act 2014 – http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

NHS bodies and NHS Foundation Trusts should:

- Look at people's experiences of the autism diagnostic process locally and assure themselves that this is acceptable, for example, involving NHS England local audit teams.

Additional information on good practice in delivering training effectively

NICE guidelines

2.9. To help standardise and improve the care and management of autism, and to enable health and social services to support people with autism more effectively, NICE has published three clinical guidelines on autism and a quality standard.

2.10. NICE has also produced:

- An Implementation Pack:[16] developing a multi-agency local autism team, to support local areas;
- A series of costing tools;[17]
- Support for Commissioning[18] which outlines the key actions that commissioners should take to deliver the quality improvements outlined in the NICE quality standard;
- A Quality Standard on Autism;

A Quality Standard on Autism describes the high-priority areas for quality improvements in the defined care area of autism support. Each standard consists of a prioritised set of specific, concise, underpinning, comprehensive recommendations, designed to support the measurement of improvement in diagnosis. These importantly include specific reference to people with possible autism needing a diagnostic assessment by an autism service (locally defined) having the assessment start within 3 months of a referral, in which people identified as potentially having co-existing physical or mental health conditions should in addition receive an assessment of such needs. These therefore contribute to improvements in the holistic health and social care outcomes defined in national outcomes frameworks, and enable commissioners to address service provision gaps, and address best practice evidence-based care.

Guidance for Commissioners of Diagnostic Services for Adults with Autism

2.11. The Joint Commissioning Panel for Mental Health (JCP-MH) will publish soon a guide to support CCGs (with their local authority partners) to commission effective diagnostic and post diagnostic services in ways that achieve better health outcomes for adults with autism.

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[16] Developing a multi-agency local autism team implementation pack – https://www.nice.org.uk/guidance/cg128/resources/autism-developing-a-multiagency-local-autism-team-implementation-pack

[17] NICE guidelines [CG142]: Autism: recognition, referral, diagnosis and management of adults on the autism spectrum – costing tools and templates https://www.nice.org.uk/guidance/cg142/costing

[18] QS51 Autism: support for commissioning – http://www.nice.org.uk/guidance/qs51/resources/qs51-autism-support-for-commissioning2

2.12. The JCP-MH guide will show how CCGs can specify the core components of the agreed NICE compliant diagnostic assessment process and referral protocols to be used by healthcare professionals with expertise in supporting people with autism and co-existing mental or physical health problems, following initial screening by primary care and non-autism specialist community teams.

Good practice for diagnostic services

Good practice for diagnostic services should include:

- Appropriately trained health professionals;
- Access where necessary to multi-disciplinary team-based support that enables individual approaches based on a range of multi-professional expertise and relevant skills;
- Making use of a structured developmental history (using if necessary a valid autism-specific information-gathering tool e.g. Diagnostic Interview for Social and Communication Disorders (DISCO));
- Assessments by interaction with, and observations of, the person with autism (using if necessary a valid structured tool e.g. Autism Diagnostic Observation Schedule (ADOS));
- Physical examinations according to relevant clinical judgement and symptoms;
- Systematic assessments of co-existing conditions;
- Any other assessments required to create a full profile of the individual's strengths, skills, impairments and support needs – that can then be used to create a needs based positive person centred support and management plan that takes account of the context of the individual's life;
- Active involvement of people with autism, family members or carers, and the use of documentary evidence or records of early development and past/current behaviours (especially experiences of home life, education and social care);
- Communication of assessment findings and recommendations, using accessible information and approaches.

2.13. In line with NICE guidelines, it is now understood that it is not only specialist professionals trained in autism who can participate in the autism diagnosis process. However where a person presents with evident complex health and care and support needs, access should be commissioned, and be available, to more comprehensive assessment by local dedicated specialist autism professionals or multi-disciplinary diagnostic teams, resulting in further 'higher level' specific support recommendations and/or access to specialist autism case coordination and interventions.

3. Planning in relation to the provision of services for people with autism as they move from being children to adults

3.1. Transition to adulthood is a crucial stage in the lives of all young people, and a time when those with autism may face particular challenges. Good transition support for children and young people with autism can have a profound impact on their ability to reach their potential, through access to further learning or training, employment and independent living. Co-operation between the relevant authorities is crucial if the person is to fulfil their potential. Local authority children's and adult services, children's health services and social care all need to play a part.

3.2. The Children and Families Act 2014 provides for a new special educational needs and disability (SEND) support system, covering education, health and social care. Under the provisions of that Act, a young person (someone over compulsory school age and under 25) can ask the local authority to assess their Education, Health and Care (EHC) needs. Others, including schools and colleges, can also make such a request. This is with a view to an EHC plan being drawn up for the young person that sets out the special EHC provision required. The young person can further expect, when an EHC plan is being drawn up, to be able (subject to certain limited criteria being met) to choose which school or further education (FE) college they are to attend. They will also be given the opportunity of a Personal Budget to control some of the provision set out in an EHC plan.

3.3. However, local authorities, NHS bodies and Foundation Trusts need to recognise that not all young people with autism will have EHC plans. Receiving support in making the transition to adulthood, and accessing appropriate services as an adult should not be dependent having an EHC plan. Indeed the Care and Support statutory guidance, issued under the Care Act, sets out that local authorities should consider how they can identify young people who are not receiving children's services who are likely to have care and support needs as an adult. The guidance identifies young people with autism whose needs have been largely met by their educational institution as an example.[19] Not everyone with autism will have an EHC plan, but this should not prevent planning for supporting the transition from children's, to adult, services.

3.4. NHS bodies and Foundation Trusts should seek to ensure that there are arrangements in place for routine support for any young person with a complex care need including those with autism in receipt of children and adolescent mental health services, in making the transition to adulthood, and adult services,

3.5. Where individuals do not fulfil referral criteria for adult services, there should be clear signposting to other sources of support and information; however, commissioners should also be vigilant to spot discontinuities between provision for young people and adults.

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[19] Care and Support Statutory Guidance – issued under the Care Act 2014 (Page 306): https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/366104/43380_23902777_Care_Act_Book.pdf

3.6. Young people with autism, whether they have an EHC plans or not, can expect to be helped with their transition from school or college to adulthood. Local authorities have duties under the Children and Families Act 2014 at the annual reviews of a child's EHC plan from Year 9 (age 13 to 14) onwards to consider what provision is required to help the child or young person in preparation for adulthood and independent living. Indeed, the expectation is that consideration of preparation for adulthood should begin right from the earliest point that special educational needs are identified.

Local Authorities must:

[20]

Under the Children and Families Act 2014 carry out the following duties, including duties which are relevant to children and young people with autism and their families:

- have regard to the *Special educational needs and disability code of practice: 0 to 25 years*[20], including the chapter on Preparing for adulthood from the earliest years;
- take account of the views, wishes and feelings of children, young people and parents when carrying out their functions under Part 3 of the Act in relation to children and young people with SEND;
- keep the educational and care provision for these children and young people under review, consulting young people directly;
- make advice and information available to children, parents and young people, including advice and information which will help young people make the transition from school;
- review EHC plans annually. From at least Year 9, the annual review must include a consideration of the preparation for adulthood, including employment/higher education, independent living and participation in society. Transition planning must be built into the plan;
- focus on progress towards the achievement of outcomes in an EHC plan; and for those over 18 assess whether the educational and training outcomes have been achieved;
- make arrangements for ensuring co-operation between officers of the local authority who exercise functions which relate to helping the young person achieve a successful transition;
- publish a "Local Offer" of educational, health, care and training provision available to these children and young people from their areas and consult children, young people and parents in drawing up and reviewing the Local Offer. The Local Offer must include information about preparation for adulthood and independent living, and the arrangements for supporting young people moving from receiving social care services for children to receiving services for adults; and
- put in place – in co-operation with local partners – arrangements relating to the right of the parents of children and of young persons with an EHC plan to request a Personal Budget.

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[20] https://www.gov.uk/government/publications/send-code-of-practice-0-to-25
Special educational needs and disability code of practice: 0 to 25 years

Under the Care Act 2014:

- carry out a child's needs assessment (also known as a transition assessment) where it appears to them that the person under 18 (referred to as a "child" in this Act but referred to as a "young person" in this guidance) is likely to have care and support needs after turning 18 and they are satisfied that it would be of significant benefit to that young person to do so. Young people with autism are identified by the Care and Support statutory guidance as a group whose members may not have received support as a child but who may have care and support needs in adulthood.[20]
- The assessment must look at whether that young person is likely to have such needs after turning 18 and, if they do, assess what those needs are likely to be and which are likely to be eligible needs. This duty applies to all young people with autism, not just those with an EHC plan. Local authorities must also continue to provide any children's care and support services the young person has been receiving under children's legislation until a conclusion is reached about whether or not the young person has needs for adult care and support and, if so, until those needs which are going to be met are beginning to be so met.

Clinical Commissioning Groups must:

- work with children and young people with special educational needs or disability and their families, and local authority partners, to carry out EHC assessments and draw up EHC plans, including transitional support for young adults.
- jointly commission with local authorities provision for children and young people with SEND including the development of a Local Offer of services.
- secure the health provision set out in an EHC plan.
- have regard to the *Special education needs and disability code of practice: 0 to 25 years*.

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[21] Care and Support Statutory Guidance - issued under the Care Act 2014 (Page 306): https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/366104/43380_23902777_Care_Act_Book.pdf

NHS bodies and NHS Foundation Trusts must, under the Children and Families Act 2014:

- have regard to the *Special education needs and disability code of practice: 0 to 25 years*;
- co-operate with local authorities, for example, when EHC assessments are being carried out, when local authorities secure the special educational provision set out in EHC plans, when transition to adulthood is being discussed for children with EHC plans and in the production of the Local Offer;
- jointly commission services for disabled children and young people and those with SEN; and
- arrange the health provision set out in an EHC plan.

Additional information on good practice on providing services for children and young people with autism as they move to being adults

3.7. The starting point for all those supporting a child or young person with autism through transition should be to aim high. With high aspirations, and the right support, the vast majority of children and young people with autism can go on to achieve successful long-term outcomes in adult life. Local authorities should work together with education providers and their partners to help children and young people realise their ambitions in relation to:

- higher education and/or employment – including exploring different employment options, such as support for becoming self-employed and help from supported employment agencies;
- independent living – enabling people to have choice and control over their lives and the support they receive, their accommodation and living arrangements, including supported living;
- participating in society – including having friends and supportive relationships, and participating in, and contributing to, the local community; and
- being as healthy as possible in adult life.

3.8. Research by the University of York,[22] commissioned by the Department of Health to inform the implementation of Fulfilling and Rewarding Lives, identified the services most valued by young people with autism in preparing for adulthood, particularly those with Asperger Syndrome and high functioning autism. These include:

- Help with facing and planning for adult life;
- Specialist, and on-going employment support;
- Peer support and opportunities to spend time with other with the same diagnosis;

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[22] Beresford, B., Moran, N., Sloper, P., Cusworth, L., Mitchell, W., Spiers, G., Weston, K. and Beecham, J. (2013) *Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions*, Working Paper, no: DH 2525, Social Policy Research Unit, University of York, York. http://php.york.ac.uk/inst/spru/research/summs/transitionsASC.php

- Voluntary work placements in settings where autism was understood and accommodated.

3.9. The research emphasised the importance of autism specific services, delivered by autism trained professionals throughout the transition process.

Transition from school: need for a person-centred approach

3.10. It is crucial to listen to the views of children, parents and young people as arrangements are made for transitions from school, using a person-centred approach. The process should allow the person with SEND to express what they would like to happen in the future and get them actively involved. Where the person has an EHC plan, they will need to be involved before, during and after review meetings. The approach should be all about listening to the person and what they want for their life and the future, with family, friends, supporters and professionals working together with them to make this happen. Children and young people should be provided with any appropriate support to help them express their views on the transition to adult life.

Transition planning

3.11. Planning for transition should start early, and for children with EHC plans, must start in Year 9.

3.12. Agencies across education, health and care should work together, perhaps setting up a transition pathway, to support good transitions to adulthood. Transition planning should cover all relevant areas of service provision, including housing and employment support.

3.13. The local authority should co-operate with health services to ensure that young people's EHC plans and health care plans are aligned.

3.14. Local authorities should consider effective planning for the transition to adult health and care services and, where a young person with autism is nearing the end of formal education, consider good exit planning when carrying out transition planning.

3.15. Local authorities should work with schools, colleges and other post-16 providers, as well as other agencies, to support young people to participate in education or training and to identify those in need of targeted support to help them make positive and well-informed choices.

Information for children, young persons and parents

3.16. Children, parents and young people should be provided with information about the provision that is available on transitions to adult life, for example, through the Local Offer.

3.17. Voluntary organisations, such as the National Autistic Society and Ambitious about Autism, can give advice to individuals who are making the transition between school and adult provision/life.

Information, advice and guidance on career choice

3.18. A key element of successful transition is the provision of excellent careers information, advice and guidance. Schools and colleges must secure independent careers guidance – for schools this applies to pupils in Years 8-13, and colleges all students up to the age of 18 and 19-25 year olds with a Learning Difficulty Assessment (LDA) in place or with an EHC plan. Schools and colleges should seek to raise the career aspirations of their SEND students and broaden their employment horizons. They should use a wide range of imaginative approaches, such as taster opportunities, work experience, mentoring, exploring entrepreneurial options, role models and inspiring speakers.

Local Offer

3.19. Local authorities should seek input from Autism Partnership Boards from the outset of developing and then reviewing Local Offers. By bringing together several organisations to deal specifically with improving services for people with autism, the boards provide a useful forum to gain feedback and expertise on proposals.

Study programmes

3.20. Post-16 providers (including school sixth forms) are expected to offer all students a study programme which is coherent, appropriately challenging, and supports the progression of the individual. Study programmes are programmes of learning for 16-19 year olds, or 16-25 year olds where the student has an EHC plan (or a statement or LDA issued under the previous SEND regime). They are based on a young person's prior attainment and designed to meet clear educational and career aspirations.

3.21. Each learner should have a study programme which is personalised to meet their own individual needs, and which offers them the best opportunities to progress successfully to life beyond school or college. It is good practice to provide opportunities which go beyond the classroom – for example, work placements with employers or voluntary placements with community organisations.

3.22. Colleges that offer courses which are designed to provide pathways to employment should have a clear focus on preparing students with SEND for work. This includes identifying the skills that employers value, and helping young people to develop them. Further information is contained in this factsheet[23] on study programmes for young people with SEND.

Employment

3.23. Achieving paid employment not only brings young people financial independence, but it can be key to building confidence and self-esteem, increasing health and well-being, and to gaining friendships and a social life. There are also benefits for the economy, employers, families, the local community and wider society.

3.24. Two study programmes with a specific vocational focus to support young people into employment are supported internships and traineeships.

- Supported internships[24] are a structured study programme based primarily at an employer. They enable young people aged 16-24 with a statement or LDA or EHC plan to achieve sustainable paid employment by equipping them with the skills they need for work, through learning in the workplace. Supported internships are unpaid, and last for a minimum of six months. Wherever possible, they support the young person to move into paid employment at the end of the programme. Alongside their time at the employer, young people complete a personalised study programme which includes the chance to study for relevant substantial qualifications, if appropriate, and English and maths.

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[23] Study programmes factsheet – http://www.preparingforadulthood.org.uk/resources/pfa-resources/factsheet-study-programmes-for-students-with-learning-difficulties-andor-disabilities

[24] What are supported internships? – http://www.preparingforadulthood.org.uk/what-we-do/supported-internships/dfe-information-for-employers

- Traineeships[25] are designed to help young people who want to get an Apprenticeship or job but don’t yet have appropriate skills or experience. They are a mainstream education and training programme with work experience that is focused on giving young people the skills and experience that employers value. At the core of a traineeship is work preparation training, English and maths for those that need it and a high quality work experience placement.

3.25. In addition to this, Apprenticeships allow young people or adult learners to earn while they learn in a real job, whilst also gaining a qualification. The Government is committed to making Apprenticeships inclusive and accessible[26] to all.

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[25] Find a traineeship – https://www.gov.uk/find-traineeship

[26] Employer toolkit for inclusive and accessible apprenticeships – https://www.gov.uk/government/collections/apprenticeships-equality-and-diversity

4. Local planning and leadership in relation to the provision of services for adults with autism

4.1. In line with the 2010 statutory guidance, *Think Autism* highlights the role local authorities and NHS bodies should have in planning services for adults with autism. In particular, local authorities and NHS bodies should develop commissioning plans for services for adults with autism and review them annually. Local authorities should also allocate responsibility to a named joint commissioner/senior manager to lead commissioning of care and support services for adults with autism.

4.2. In addition, local commissioning plans should set out how local authorities will ensure that adults with autism are able to access direct payments (where appropriate) and benefit from the personalisation of health and social care. Local partners should already have a local autism partnership board in place, which brings together different organisations, services and stakeholders and adults with autism and their families to set a clear direction for improved services. Autism partnership boards have proved to be a highly effective means for stakeholders to shape and monitor local delivery of the strategy and statutory guidance. It is therefore essential for their partnership arrangements to be established in areas where they are not currently.

4.3. Services should support an individual to achieve the outcomes identified across the spectrum of needs aligned with the local offer and market position statements. These describe what local resources are available for people in the local community to access.

4.4. It is important that parents, young people and adults with autism can access information that is relevant to them to help them make choices about the type of support they can receive.

4.5. Health and social care services need to recognise the impact that autism has on an individual's life and consider this alongside any additional needs such as a learning disability or mental health condition ensuring that there is a personalised approach with targeted support. In addition, Health and Wellbeing Boards should work with NHS bodies and Foundation Trusts to raise awareness and make reasonable adjustments to enable people to access appropriate services in their local community.

Health and Wellbeing Boards

4.6. Health and Wellbeing Boards have a crucial role to play in overseeing implementation of the Adult Autism Strategy. As a local health and wellbeing system leader, bringing together partners from NHS England, CCGs, HealthWatch and Local Authorities, the Health and Wellbeing Board is central to ensuring the needs of people with autism are addressed locally. Health and Wellbeing Boards across the country have been developing their Health and Wellbeing strategies based on local evidence contained in their Joint Strategic Needs Assessments (JSNA) to improve the life outcomes for local people.

4.7. Achieving better outcomes for adults with autism requires local partners to work together, and Health and Wellbeing Boards are well placed to lead this joint working. With the support, guidance and leadership of Health and Wellbeing Boards the aspirations, vision and priorities of *Think Autism* can be embedded and owned locally to meet the needs of the whole community including people with autism. Planning and resource allocation systems should be designed to reflect the full range of needs, including those for people with real complex needs.

4.8. Health and Social care services should recognise how autism affects an individual's life including any additional needs arising from for example, a learning disability or mental health issue. Health and Wellbeing Boards should therefore promote people's access in their local communities working through raising awareness and accessibility through reasonable adjustments.

Local Authorities should:

- Ensure that there is a meaningful local autism partnership arrangement that brings together different organisations, services and stakeholders locally, including the CCG, and people with autism, and sets a clear direction for improved services;
- Allocate responsibility to a named joint commissioner/senior manager to lead commissioning of care and support services for adults with autism in the area, known as the autism lead. This lead should be appointed by the Director for Adult Social Services;
- Bring partners together, for example through Health and Wellbeing Boards, to ensure information sharing protocols are in place and that all necessary information for service planning is available;
- Ensure that there are appropriate arrangements in place to ensure senior level sign off for responses to the national autism self assessment exercises and other appropriate developments around the delivery of the local autism strategy.

Local Authorities must:

Under the Care Act, from April 2015

- Exercise their care and support functions with a view to ensuring the integration of care and support provision with health provision and the provision of other services that may have an effect on health (such as housing accommodation) where they consider this would, for adults in their area, promote well-being, improve the quality of care and support, or help prevent or delay the development of needs. This will apply in relation to adults with autism, as with all other adults. An example of this would be that a local authority when planning the way in which the care and support needs of an adult with autism are to be met, should consider local housing strategies and plans, and how those strategies and plans deal with adults with autism;
- Co-operate with relevant partners generally in exercise of their care and support functions, and in the case of individuals with care and support needs when requested to do so by a relevant partner, including in relation to adults with autism or their carers. These relevant partners include other local authorities, NHS bodies in the area, the police and probation service. Officers of each local authority responsible for care and support functions must also co-operate with other officers within the local authority responsible for housing, children's services and public health.

Local Authorities, NHS bodies with commissioning responsibility should jointly:

- Consider and include the number of people with autism in their area as part of the JSNA. Local partners will want to determine how they carry out responsibility locally, for example it could include such factors as identifying the age profile and range of support needs of people living with autism so as to predict how need and numbers will change over time;
- Develop and update local joint commissioning plans for services for adults with autism based on effective joint strategic needs assessment, and review them annually, for example with the local Health and Wellbeing Board;
- In developing such plans, it will typically be necessary (as a minimum) to gather information locally about:
  - The number of adults known to have autism;
  - The range of need for support to live independently;
  - The age profile of people with autism in the area – to enable local partners to predict how need and numbers will change over time (including children and young people, over 65s as well as working age).

4.9. To achieve the most accurate local information about the numbers of adults with autism and their needs, good practice suggests including the number of people with autism:

- from Black Asian Minority Ethnic (BAME) communities;
- by gender (men, women or other) including trans gender;
- in employment;
- likely to need employment support to gain or stay in work;
- placed in the area (and funded) by other local authorities;
- placed out of area by local authorities and/or NHS bodies;
- in hospital or living in other NHS-funded accommodation;
- resettled from long-stay beds or NHS residential campuses to community provision;
- living at home on their own, or with family members, or with older family carers and not receiving health or social care services.

4.10. Key professionals to engage in this evidence gathering are:

- Social care professionals;
- GPs (could identify numbers of people on their practice list who have an autism diagnosis and could also follow up with diagnostic services to find out if their patients have been given an autism diagnosis if this information has not come back after referral);
- Job centre managers;
- Employment support providers;
- Local autism groups and branches of national autism organisations.

Supporting older adults with autism

4.11. Older adults with autism are a neglected group and have received less attention through policy, research and service provision. In part, this is because autism was only identified in the 1940s and the first generation of adults to be diagnosed are only now moving into older age. It is clear that approaches to older people with autism will need to change and develop.

4.12. The key message for local authorities and NHS bodies is that they need to plan appropriate services for older people with autism who live in the area, and ensure that mainstream services used by older people are appropriate for people with autism. Data collection is integral to the success of local planning, as will be incorporating this data in to local autism strategies and commissioning plans.

4.13. Local areas should have a diagnostic pathway in place for autism. They must ensure this works for older people, who report problems in being identified, not being able to provide a developmental history and additional health problems as obstacles to receiving a diagnosis.

4.14. Older adults with autism frequently rely solely on their families and friends for support. Preventative services will be particularly important for older adults with autism who are not eligible for social care support. Furthermore, special consideration is needed when planning for the transition into older age and the increased likelihood of other health issues, particularly when family may not be around to support adults with autism.

4.15. Further information on supporting older adults with autism is available through the NAS: www.autism.org.uk.

Supporting people with autism from BAME communities

4.16. People with autism from BAME communities report the same issues accessing diagnoses and support, but these issues can be compounded if their local authorities find those communities harder to reach. Therefore, it is crucial that local authorities, NHS bodies and Foundation Trusts must take extra steps to identify the needs of their BAME population and ensure that services are designed that support people from BAME communities effectively.

4.17. In planning services, the collection of data will be vital, to make sure that local authorities have an accurate picture of their population and needs. Furthermore, local authorities, NHS bodies and Foundation Trusts should be reaching out to BAME communities, for example through champions in faith and other community networks to raise awareness of autism. The provision of information and consultation with families are key in this situation and should be provided in an accessible format. Local authorities, NHS bodies and Foundation Trusts should therefore particularly ensure that information on autism and support services are provided in additional languages, as appropriate, as well as translation and advocacy. Services should also be available in appropriate locations and at appropriate times.

4.18. Throughout this, however, it is paramount that local authorities and NHS bodies recognise that different communities will have their own specific needs.

Promoting the rights of people with autism

4.19. People with autism have the same rights as others to have their needs recognised, assessed and, where appropriate, met. Expectations should be high and services should strive to meet these expectations.

Local Authorities should:

- Using a variety of methods,[22] listen carefully to the views, wishes, feelings and beliefs of people including those with autism and their carers; this could be accomplished in part by autism partnership boards through consultation events or through online feedback forms for adults with autism who are unable to attend autism partnership boards.

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[27] The National Autistic Society ‘it involves us’ guide sets out good practice on involvement of people with autism in partnership boards. – http://www.autism.org.uk/news-and-events/news-from-the-nas/it-involves-us.aspx

Additional information on good practice in planning and commissioning effectively

4.20. In order to plan and commission services effectively, local authorities and their Health and Wellbeing Boards, CCGs and other partners need to have access to as comprehensive data on local numbers and needs as is possible. But gathering data on the numbers and needs of people with autism at a local level can be challenging. Health and adult social care services are currently likely to know of only a small number of all local people with autism. There are many reasons for this, including:

- Many people with autism are likely to be undiagnosed or misdiagnosed;
- Not all people with autism will come into contact with social care services and so local authorities are unlikely to have information on them or their needs;
- Many people, especially older adults and people from certain communities, are unknown to local authority and NHS services. This may be because they are not eligible for services provided by local authorities and NHS bodies or because they do not know what help is available, or because they rely heavily on methods to 'manage' their autism and/or family and friends;
- The way local services are organised. People with autism sit across a broad spectrum and consideration of aligned/ or comorbid conditions is needed such as learning disability or mental health services. Historically, people with autism may have approached services, but where they do not have a co-occuring learning disability or mental health problem, they are sent between teams and end up falling in between services.
- Historically, services have also not collected comprehensive data about this population. However, from April 2014 under the Adult Social Care Outcome Framework,[28] local authorities must now record information about a person's primary reason for support and whether the person has reported certain other health conditions, such as autism or other hidden impairments. This will initially include autism generally and detail Asperger syndrome if that information is known. It is essential that local authority systems record this information to ensure that over time there is a better understanding of the local population of adults with autism.

4.21. There is other action that local authorities, NHS bodies and Foundation Trusts in each area can take to gather effective data at a local level to plan and deliver the right services for local needs, including on those people with low level needs who are not eligible for care and support. Local estimates of prevalence can be calculated from national data. This can be useful as it allows local authorities to estimate unmet need. To do this, local authorities can use PANSI[29] (Projecting Adult Needs and Service Information), a database that uses national data to make projections on the possible impact of demography and certain conditions on local populations. In order to collect data on the older population, local authorities could also use the Projecting Older People Population Information System

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[28] Adult Social Care Outcome Framework 2014 to 2015 – https://www.gov.uk/government/publications/adult-social-care-outcomes-framework-2014-to-2015

[29] PANSI (Projecting Adult Needs and Service Information) – http://www.pansi.org.uk/

(POPPI),[30] which includes projections of prevalence of autism among older people.

4.22. Local authorities can also work with local groups such as those that provide advocacy services and befriending services to gather information about the number of people they help.

4.23. Housing can play a vital role in supporting people with autism to maintain good health, independence and improve quality of life. From April 2015, section 2 of the Care Act will place a duty on local authorities to provide or arrange services, facilities or resources, or take other steps, to contribute towards preventing, delaying and reducing the needs for care and support of adults in their areas. Sections 6 and 7 of the Care Act will require local authorities to ensure the co-operation of their officers who exercise care and support functions with their officers who exercise housing functions both generally and in specific cases, and provide for local authorities to co-operate with other relevant partners or persons, such as private registered providers of social housing. Further, local authorities will be required to exercise their functions, under section 3 of the Care Act, with a view to ensuring integration between the provision of care and support, health services, and health related services such as the provision of housing, where they consider that doing so would promote the wellbeing of adults in their area with care and support needs, contribute to the prevention or delay of the development of such needs or improve the quality of care and support for adults.

4.24. To be meaningful, Autism Partnership Boards should comprise sufficiently senior representatives from local authorities and have NHS representation. These members should also consistently attend meetings. People with autism, their families and carers should also be fully included. In order to involve people with autism, local authorities should consider what reasonable adjustments need to be made.

4.25. Guidance involving people with autism has been created by the National Autistic Society which looks at partnership boards and wider engagement in local autism plans and can be downloaded via the following link: http://www.autism.org.uk/news-and-events/news-from-the-nas/it-involves-us.aspx

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[30] Projecting Older People Population Information System (POPPI) – http://www.poppi.org.uk/

5. Preventative support and safeguarding in line with the Care Act 2014 from April 2015

5.1. Preventative support is important for people with autism. When people with autism do not have the right preventative support, the result can be that they can spiral into mental health crises with parents/carers left to pick up the pieces or, if they are not available, expensive and inappropriate inpatient admissions or even contact with the criminal justice system may result.

5.2. Furthermore, changes such as bereavement, moving home, getting married or divorced, having children or becoming unemployed can have a particularly significant effect on someone with autism. Everyday life may also create stresses that affect someone with autism, for example relationships in the workplace. Preventative support can help people with autism to manage such events and day-to-day life better.

5.3. From April 2015, section 2 of the Care Act will place a duty on local authorities to provide or arrange preventative services for people within their communities. In discharging their duties on prevention, local authorities should, in particular, ensure they are considering the needs of their local adult population who have autism, including those who do not meet the eligibility threshold for care and support.

5.4. The term “prevention” or “preventative” measures can cover many different types of support, services, facilities or other resources. There is no one definition for what constitutes preventative activity and this can range from wide-scale whole-population measures aimed at promoting health, to more targeted, individual interventions aimed at improving skills or functioning for one person or a particular group or lessening the impact of caring on a carer’s health and wellbeing. In considering how to give effect to their responsibilities, local authorities should consider the range of options available, and how those different approaches could support the needs of people with autism.

5.5. “Prevention” is often broken down into three general approaches – primary, secondary and tertiary prevention as described in more detail in the Care and Support Statutory Guidance[31] issued under the Care Act 2014.

5.6. Preventative support can be provided in many different ways. Many adults with autism find it difficult to make friends. User-led and voluntary support groups help adults with autism build relationships with peers, friends, partners and colleagues and also support independent living and being part of the community. These are all part of preventative support systems, although they are only one part. Such support should form part of a comprehensive range of preventative support and be accessible and provide choice, for example, by ensuring there are a number of support options across a geographical area. Local authorities, NHS bodies and Foundation Trusts may find NICE shared learning examples useful.

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[31] Care and Support Statutory Guidance issued under the Care Act 2014 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/315993/Care-Act-Guidance.pdf

5.7. It is important that all people with autism, whatever their level of need, can easily access information in their local area about what support from peers, charities or other community groups is available. The establishment and maintenance of a service for providing people in their area with information relating to care and support for adults is a duty which will be imposed on local authorities from April 2015 (under section 4 of the Care Act 2014).[32]

5.8. It is critical to the vision in the Care Act that the care and support system works to actively promote wellbeing and independence, and does not just wait to respond when people reach a crisis point. It will be vital that the care and support system intervenes early to support individuals, helps people retain or regain their skills and confidence, and prevents care and support needs developing or delays deterioration in such needs wherever possible.

5.9. There are many ways in which a local authority can achieve these aims whilst promoting wellbeing and independence and reducing dependency. This guidance sets out how local authorities should go about fulfilling their responsibilities, both individually and in partnership with other local organisations, communities, and people themselves.

5.10. The local authority's responsibilities for contributing towards the prevention or delay of care and support, or support, needs apply to all adults with autism in their area, including:

- people who do not have any current needs for care and support;
- adults with needs for care and support, whether their needs are eligible and/ or met by the local authority or not;
- carers, including those who may be about to take on a caring role or who do not currently have any needs for support, and those with needs for support which may not be being met by the local authority or another organisation.

Under the Care Act Local Authorities must:

- Provide or arrange services, facilities or resources, or take other steps, which they consider will contribute to preventing or delaying the development of care and support needs of adults in their area and support needs of carers, including the care and support needs of adults with autism and the support needs of their carers, regardless of whether they are eligible for social care. For example, this could be done through providing "lower level" local preventative support and enabling people with autism to be connected with peers and with other local community groups;
- Have regard to the importance of identifying existing services, facilities and resources already available which could assist with carrying out the duty above, as well as the importance of identifying adults in its area (including those with autism) with care and support needs which are not being met. To do this effectively they should consult with adults with autism and their carers, in order to establish what support already exists and what needs are not being met, to help determine what preventative services etc. are needed.

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[32] Part 1 of the Care Act 2014 – Section 4 – http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

Local Authorities should:

- Ensure that they include in local autism plans or strategies how people can access local autism advice and information easily in a way that is appropriate and identifiable for people with autism.

NHS Bodies and NHS Foundation Trusts should:

- Ensure that health and care staff who are highly likely to support people with autism, such as GPs, psychiatrists, counsellors and psychiatric nurses are appropriately trained beyond general basic awareness about autism;
- Ensure that people with autism have equal access to local psychological therapy services, such as Improving Access to Psychological Therapies (IAPT).[28] If an IAPT service can't help a person with autism or Asperger syndrome directly, arrangements should be made so that other appropriate local services can provide support.

Additional information on good practice in delivering preventative support and advice effectively

- Services based around low-level interpersonal support, such as buddying schemes, have enabled many adults with autism to participate in different social and leisure activities, and promoted social inclusion and wellbeing. Access to these networks and to advice and information is vital to help people access the communities in which they live. It can also help to prevent people going into crisis situations, which can have a very detrimental impact on individuals and can be very costly for local authorities and NHS bodies.
- People with autism and their families have also told us that it can be hard sometimes to know where to go for advice and information locally as they do not fit into locally-used "boxes" or categories such as learning disability or mental health. Autism strategies developed by local authorities should ensure that they include how people with autism but without additional learning disabilities or mental health issues can access such advice and information easily in a way that is appropriate for them. One such example could be a one-stop shop that provides a safe and friendly place to speak confidentially to someone who understands autism, access, guidance and information about services, one to one sessions, workshops, training days and group activities for families, children and professionals; these have successfully been implemented in some parts of the UK and have received positive feedback from adults with autism.
- A revised Mental Health Act 1983 Code of Practice[34] was published on 16 January 2015 and will come into force on 1 April

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[33] See the National Institute for Clinical Excellence (NICE) recommendations – http://www.nice.org.uk/

[34] The Mental Health Act 1983 Code of Practice https://www.gov.uk/government/publications/code-of-practice-mental-health-act-1983

2015. It has been prepared in accordance with section 118 of the Mental Health Act 1983. Chapter 20 of the Code addresses the particular key issues from the Act and Mental Capacity Act which are relevant to people with autistic spectrum conditions for professionals to ensure independence, dignity and respect to those they treat and assess.

- Many people with autism who have been detained under specific sections of the Mental Health Act will require, and be entitled to aftercare. Discharge planning for people with autism should begin when the person is admitted and involve health and local authorities to work together in the interests of an individual to ensure appropriate community-based support is in place before discharge. This will require assessment by a practitioner with expertise in autism.

Mental Health

5.11. People with autism are more likely to have mental health needs than the wider population, but may have problems using mental health services because of the way they are organised and run. Preventative mental health services can prevent people with autism going into a crisis.

5.12. Practical materials designed to help improve the quality of mental health services for adults with learning disabilities and adults with autism have been developed by the National Development Team for Inclusion (NDTi). Reasonably Adjusted? – published in 2012, sets out the reasonable adjustments mental health services have put in place for people with learning disabilities and people with autism. In addition, the NDTi have produced materials to help services review their own quality and share and replicate good practice known as the Green Light Toolkit (2013) it consists of an audit framework and guidance for making service improvements to mental health services and provides material designed to help improve the quality of mental health services for adults with learning disabilities and adults with autism. Full details of both reports can be downloaded from the NDTi website,[35] along with summaries aimed at different audiences such as Health and Wellbeing Boards.

5.13. Reasonably Adjusted?[36] is a database on the Improving Health and Lives Learning Disabilities Observatory (IHAL) website with downloadable examples of types of reasonable adjustments for people with learning disabilities and people with autism who need mental health services and support.

Mental Health Crisis Care Concordat

5.14. The Mental Health Crisis Care Concordat[37] is a national agreement between local services and agencies involved in the care and support of people in mental health crisis. It sets out how organisations can work together better to make sure people get the help they need when they need it. The document sets out the principles and good practice that should be followed by health staff, police officers and approved mental health professionals when working together to help people in a mental health crisis.

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[35] Reasonably Adjusted (2012) & Green Light Toolkit (2013) http://www.ndti.org.uk/news/national-news/green-light-toolkit/

[36] Reasonably Adjusted? www.ihal.org.uk/mhra/

[37] Mental Health Crisis Care Concordat https://www.gov.uk/government/publications/mental-health-crisis-care-agreement

Helping people with autism to keep safe

5.15. Local authorities and others must work together to help and protect people with care and support needs, who may be at risk of abuse or neglect as a result of those needs. But this should not prevent such people from making their own choices and having control over their lives wherever possible. Everyone in the community should understand the importance of safeguarding and helping to keep people safe.

5.16. The local authority must make information and advice available on how to raise concerns about the safety or wellbeing of an adult who is at risk of abuse or neglect because of their needs for care and support and should support public knowledge and awareness of different types of abuse and neglect and how to keep or support people with care and support needs to be physically, sexually, financially and emotionally safe. This information and advice should also cover who to tell when there are concerns about abuse or neglect and what will happen when such concerns are raised, including information on how the local Safeguarding Board works.

5.17. The Care Act makes the local authority's adult safeguarding duties statutory, in recognition of the need to proactively help and protect people with care and support needs, including people with autism, to keep safe from the risks of abuse or neglect. It places the establishment of Safeguarding Adults Boards on a statutory footing, so as to ensure local authorities, CCGs and chief police officers work together to develop and implement adult safeguarding strategies. This will better prepare local agencies who have relevant care and support functions both to prevent abuse or neglect and to respond to it when it occurs.

5.18. Further information on Safeguarding can be found in Chapter 14 of the Care and Support Statutory Guidance[38] issued under the Care Act 2014.

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[38] Safeguarding Chapter 14 of the Care and Support Statutory Guidance issued under the Care Act 2014 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/315993/Care-Act-Guidance.pdf

Local Authorities must:

- Establish a Safeguarding Adults Board[34] for its area (under section 43 of the Care Act);
- Make enquiries (or arrange for most appropriate person to carry out enquiries), where they have reasonable cause to suspect an adult in their area who has needs for care and support is experiencing or at risk of abuse or neglect and as a result of their needs is unable to protect themselves against the risk of abuse or neglect; this must consider what, if any, action should be taken in the adult's case, and who should take such action (under section 42 of the Care Act);[35]
- Ensure that, where actions required to protect an adult with autism are identified through a safeguarding enquiry, they or the appropriate person takes the appropriate action to do so.

Local Authorities, NHS bodies and NHS Foundation Trusts should:

- Support wherever possible and appropriate when working with individuals and families to understand, recognise and prevent risk. Including knowing how to raise concerns and report problems. Examples include young people with autism transitioning into adulthood from children's services. Those who may not be eligible for care and support but should be able to access universal and primary care services such as GPs and others who can advise them as part of their transition plan.

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[39] Safeguarding Adults Board http://www.legislation.gov.uk/ukpga/2014/23/section/43/enacted

[40] Part 1 of the Care Act 2014 – Section 42 – http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

6. Reasonable Adjustments and Equality

6.1. For many people with autism, mainstream public services can be hard to access. This can be due to a lack of understanding of autism among staff in those services but there are other contributory factors.

6.2. People with autism can have a number of sensory differences affecting all five senses that can impact on their lives in a number of ways including communication, socialising and living independently: for example they can be hypersensitive to light, smell, touch and noise; they can have significant difficulties with communication and can struggle with verbal or written language, for example instructions in forms or standard letters.

6.3. Under the Equality Act 2010,[41] all public sector organisations, including employers and providers of services, are required to make reasonable adjustments to services with the aim of ensuring they are accessible to disabled people, including people with autism. People with autism have a right to access mainstream services just like anyone else. There are other relevant duties that local authorities, NHS bodies and Foundation Trusts are under, as set out below, which should have a positive impact on the access which people with autism have to health and social care services. This is, at its core, about equal rights.

6.4. Without reasonable adjustments many services can be inaccessible for adults with autism. Putting in place reasonable adjustments can ensure that adults with autism are able to benefit fully from mainstream public services to live independently and healthily. For clarification, the reasonableness or otherwise of an adjustment depends on the consideration of how effective the change will be in assisting disabled people in general or a particular service user, whether it can actually be done, its cost, and the organisation's resources and size. Further explanation is provided by the Equality and Human Rights Commission (EHRC)[42] on what is meant by 'reasonable':

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[41] Equality Act 2010 – http://www.legislation.gov.uk/ukpga/2010/15/contents

[42] Equality and Human Rights Commission http://www.equalityhumanrights.com/your-rights/service-users/adjustments-disabled-people/what-meant-%E2%80%98reasonable%E2%80%99

Local Authority, NHS bodies and NHS Foundation Trusts must:

- Comply with all the duties which apply to them under the Equality Act 2010, including:-
    - the duty to make reasonable adjustments to their services (whether they provide these services directly or outsource them) for disabled persons (such as those with autism); and;
    - the Public Sector Equality Duty[38] (the Equality Duty) created by the Equality Act 2010. This requires public authorities to have due regard to the need to, in exercising their functions, eliminate discrimination, harassment, victimisation and any other unlawful conduct under the Equality Act, advance equality of opportunity between persons e.g. who are disabled and those who are not, and foster good relations between e.g. persons who are disabled and those who are not.

6.5. From 1st April 2015, the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014[44] provide that service users must be treated with dignity and respect and in particular a registered person must have due regard to any relevant protected characteristic (such as disability) of the service user. They also provide that care or treatment for a service user must not be provided in a way that includes discrimination against a service user on grounds of any protected characteristic, such as the disability of that service user.

NHS England and CCGs must:

- Under the National Health Service Act 2006,[40] have regard to the need to reduce inequalities between patients with respect to their abilities to access health services and reduce inequalities between patients with respect to the outcomes achieved for them by health services being provided. This should positively affect the way that these bodies exercise their functions in respect of people with autism.

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[43] Public Sector Equality Duty http://www.equalityhumanrights.com/about-us/about-commission/equality-and-diversity/public-sector-equality-duty

[44] Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/274719/Regs_draft.pdf

[45] Sections 13G and 14T of the National Health Service Act 2006 – http://www.legislation.gov.uk/ukpga/2012/7/section/23/enacted

NHS Foundation Trusts should:

- As stated in the Risk Management Assessment Framework (2009) (Monitor's risk assessment framework 3),[41] have ways of identifying and flagging up people with autism, including those who have learning disabilities, and have protocols that ensure pathways of care are reasonably adjusted to meet needs, along with accessible information about treatment options, complaints procedures and appointments.

Further information on good practice in delivering reasonable adjustments effectively

6.6. Each adult with autism is different and will have different needs that require reasonable adjustments to be made. Local authorities, NHS bodies and Foundation Trusts should work with each individual with autism to identify what reasonable adjustments should be made, which can include changes to:

- premises – taking account of hypersensitivities and providing quiet or lower-light areas;
- processes – scheduling appointments at less busy times, ensuring that the appointment is on time, allocating extra time to adults with autism and being flexible about communication methods, for example, less reliance on telephone- based services, appointments should run on time, with the flexibility to swap appointments around to ensure timekeeping;
- face-to-face communications – some people with autism would rather communicate non-verbally even in face-to-face consultations; avoiding ambiguous questions, asking follow-up questions where further information is needed, being aware of sensitivity to touch, providing written information in advance of meetings are all helpful;
- written communications – ensuring essential documents and forms are available in accessible formats, in particular, easy read versions and formats that take account of sensory issues in their choice of colours, as set out in the statutory information standard at:– http://www.england.nhs.uk/ourwork/patients/accessibleinfo-2 written information could also be used to reinforce what was said in a face-to-face consultation, to enable adults with autism to process it.
- planning and preparation – offering opportunities for adults with autism to visit settings in advance to familiarise themselves with what to expect: for example visiting a council building in advance of a social care assessment, visiting a court prior to giving evidence or an optician's prior to an eye test.
- As part of *Think Autism*, the Department of Health's update to the Adult Autism Strategy, the National Autistic Society produced a guide to help local authorities better involve people with autism in their local planning and implementation. The guide is called *it involves us: Enabling meaningful inclusion of adults with autism in the development of local autism*

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[46] Monitor's risk assessment framework 3 – https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299929/RAF_Update_AppC_1April14.pdf

plans[47] it provides local authorities and other partners guidance on involving and engaging people with autism, both through Autism Partnership Boards and through wider consultation.

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[47] *It involves us: Enabling meaningful inclusion of adults with autism in the development of local autism plans* http://www.autism.org.uk/news-and-events/news-from-the-nas/it-involves-us.aspx

7. Supporting people with complex needs, whose behaviour may challenge or who may lack capacity

7.1. People with autism or learning disabilities, who also have mental health conditions or behaviours viewed as challenging are entitled to get good quality safe care, whether at home, living in the community or in hospital. This section provides guidance on how to effectively support individuals with the most complex needs wherever they are receiving care and treatment. A number of studies and investigations have found that too many people with autism, including those who may have behaviour that others find challenging, or who have complex needs, continue to be placed in hospitals for assessment and treatment, in some cases, for many years, often far from where they wish to be placed and often received poor quality care.[48]

7.2. People with autism should be assessed, treated and cared for in the community wherever possible, and when they need to go into inpatient care it should be for the minimum time necessary and in a facility close to their home. Having complex needs does not mean people should go into long-term inpatient, residential care or assessment and treatment centres inappropriately or indefinitely.

7.3. People should live in their own homes with support to live independently if that is the right model of care for them. Behaviour others may find challenging lessens with the right support and individuals benefit from personalised care and living in the community. Specialist hospital settings should only be offered as a last resort, when essential and only for assessment and treatment. Discharge planning for people with autism should begin when the person is admitted and involve local authorities, NHS bodies and Foundation Trusts in working together in the interests of an individual to ensure appropriate community-based support is in place before discharge. Services that can meet the needs of people with complex needs are essential to minimising the use of secure health settings.

7.4. It is important that those who support people with complex needs, whose behaviour may challenge or who may lack capacity should have a good understanding of supported decision-making; understand the principle that people should not be treated as lacking capacity simply because they make an unwise decision; should consider their wishes and feelings; and all health and social care organisations need to understand the principle of least restrictive care – which means identifying a range of interventions and seeking the least restrictive ones for people with autism.

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[48] The Learning Disability Census 2014 showed that on 30 September 2014, there were 308 people with a diagnosis of autism and 908 people with a diagnosis of learning disability and autism in a mental health hospital – http://www.hscic.gov.uk/catalogue/PUB16760

The Transforming Care Programme[49] sets out suggested ways for improving the quality of care for people with learning disabilities and or autism. These include Local Authorities, NHS bodies and NHS Foundation Trusts:

- Putting in place arrangements to review all current inpatient placements and support everyone found to be inappropriately placed in a hospital setting to move to community-based support;
- Working together to put in place a locally agreed joint plan to ensure high-quality care and support services for all people with challenging behaviour. This would include appropriate housing in the community underpinned by joined up commissioning and funding arrangements across local authorities and NHS commissioners and as appropriate self-funding arrangements;
- Working in partnership so there is a substantial reduction in reliance on inpatient care for people with autism. This requires personalised care planning, discharge planning, the provision of alternative community-based settings for treatment and care and support provision and crisis intervention and support.

7.5. This is not just about those people currently within inpatient settings but also about ensuring support for those who may be at risk of going into them in future. Care staff both in local authority teams such as those assessing adults' care and support needs and NHS funded providers needing to have a good understanding of the Mental Capacity Act 2005[50] (MCA) in order to help people with autism.

Mental capacity

7.6. Professionals working with those with autism must be aware of and act within the MCA. Recent reports – including from the House of Lords Select Committee – have demonstrated that awareness of the MCA among health and care professionals is too low and as a result, service users are not benefitting from the rights afforded to them under the law.

7.7. The MCA is clear that professionals must assume an individual has capacity unless it is shown they lack capacity. Capacity is time and decision specific and must be reassessed as appropriate. The Act states that professionals should support those who might lack capacity to make the decision themselves. Where this proves not to be possible, professionals must consult with the individual's carers and those interested in the individual's welfare (e.g. family) in reaching a "best interests decision".

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[49] Transforming Care: A national response to Winterbourne View Hospital – Department of Health Review Final Report (2012) – https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf

[50] Mental Capacity Act 2005 – http://www.legislation.gov.uk/ukpga/2005/9/contents

7.8. Professionals must have an understanding of what restrictions may be imposed through a person's care and the need to minimise restrictions and maximise individual freedoms. In accordance with the MCA's guiding principles, that professionals who provide care to an individual who lacks capacity must consider whether the care is being provided in the least restrictive way possible to achieve the intended outcome. Where restrictions on an individual are of a degree that may amount to a deprivation of liberty, this must be authorised under the Deprivation of Liberty Safeguards or by an order of the Court of Protection under the MCA.

Local Authorities, NHS bodies and NHS Foundation Trusts must:

- Consider how to promote the article 8 right to family life[47] for people with autism, including opportunities for friendships and family contact, to a life in the community where possible, and the opportunity to develop and maintain relationships;
- Under section 67 of the Care Act,[48] local authorities must arrange for an independent advocate to be available to represent and support a person with autism for the purpose of facilitating their involvement in their needs assessment and the preparation and review of their care and support plan where they would otherwise experience a substantial difficulty in understanding relevant information, retaining that information, using or weighing that information or communicating their views, wishes or feelings (and there is nobody appropriate to support them for this purpose). This will require knowing in advance where such services can be commissioned.
- Ensure individuals are deprived of their liberty only with appropriate legal safeguards, e.g. under the Mental Health Act 1983 or MCA.

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[51] Human Rights Act 1998: Article 8 – http://www.legislation.gov.uk/ukpga/1998/42/schedule/1/part/I/chapter/7

[52] Care Act 2014: Section 67 – http://www.legislation.gov.uk/en/ukpga/2014/23/section/67/enacted?view=interweave

Local Authorities, NHS bodies and NHS Foundation Trusts should:

- Understand and take steps to implement least restrictive care options for people with autism, carefully considering how to provide appropriate care in a way that is least restrictive of the person's rights and freedom of action;[49]
- Ensure that health and care providers have clear policies on the use of restrictive interventions, and on reducing their use, and are training staff appropriately;[50]
- Ensure that services have a clear process to follow in the event of the use of restrictive interventions, including restraint, and that they are recording and reporting such instances appropriately;[51]
- Ensure staff exercising functions under the MCA have regard to the Mental Capacity Act 2005; Code of Practice 2007, and in particular, how it relates to people with autism;
- Ensure that professionals and staff performing functions under the Mental Health Act 1983 have regard to the revised Code of Practice (2015), particularly, but not limited to, the requirements that relate specifically to autism.[52]

Additional information on good practice for supporting people with complex needs, whose behaviour may challenge or who may lack capacity

7.9. Good practice guidance on supporting people with learning disabilities, autism and those with behaviour which challenge includes the 1993 Mansell report,[57] updated and revised in 2007. Both emphasise:

- the responsibility of commissioners to ensure that services meet the needs of
- individuals, their families and carers;

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[53] Advice for staff on the use of restrictive interventions for patients with difficult behaviour https://www.gov.uk/government/publications/positive-and-proactive-care-reducing-restrictive-interventions

[54] Guidance on commissioning or delivering workforce development for adult health and social care workers in England who may need to carry out restrictive practices or interventions as part of positive support for people with health and social care needs who can display or are at risk of displaying behaviour that challenges or are resisting essential care. http://www.skillsforhealth.org.uk/images/images/news/A%20positive%20and%20proactive%20workforce.pdf

[55] Positive and Proactive Care: reducing the need for restrictive interventions https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/300293/JRA_DoH_Guidance_on_RP_web_accessible.pdf

[56] Code of practice: Mental Health Act 1983 – the Code is statutory guidance to the groups listed in s.118 MHA. The legal status of the Code means that these groups must have regard to the Code. The guidance in the Code should be followed unless there are cogent reasons for departing from it.– https://www.gov.uk/government/publications/code-of-practice-mental-health-act-1983

[57] Services for people with learning disability and challenging behaviour or mental health needs [Mansell report – revised edition 2007]- http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_080129

- a focus on personalisation and prevention in social care;
- that commissioners should ensure services can deliver a high level of support and care to people with complex needs/challenging behaviour; and
- that services/support should be provided locally where possible.

7.10. The Department of Health have published guidance *Positive and Proactive Care: reducing the need for restrictive interventions*[58] for all those working in health and social care settings for commissioners of services, executive directors, frontline staff and all those who care for and support people.

7.11. The Department of Health, Skills for Health and Skills for Care have developed a guide *a positive and proactive workforce*[59] for adult health and social care workers in England who may need to carry out restrictive practices or interventions as part of positive support for people with health and social care needs who can display or are at risk of displaying behaviour that challenges or are resisting essential care.

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[58] Positive and Proactive Care: reducing the need for restrictive interventions – https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/300293/JRA_DoH_Guidance_on_RP_web_accessible.pdf

[59] A positive and proactive workforce – http://www.skillsforhealth.org.uk/images/images/news/A%20positive%20and%20proactive%20workforce.pdf

8. Employment for adults with autism

8.1. Evidence shows that being in work and staying in work is beneficial for people's health and wellbeing. People with autism, like anyone else, want to work and have a variety of skills and talents that would be valued in a range of different workplaces.

8.2. Some people with autism will require support to get or keep a job. Yet adults with autism are currently significantly under-represented in the labour market, which has a detrimental impact on their financial circumstances and social inclusion, as well as being a waste of skills and abilities. The Autism 2010 strategy and *Think Autism* included commitments aimed at increasing the number of adults with autism in work through the provision of guidance and training to employers and employment support services and ensuring adults with autism benefit from employment initiatives. The Department for Work and Pensions has since introduced the Work Programme which provides personalised back to work support for unemployed people, including disabled people. It has also established Work Choice and Access to Work,[60] both of which help disabled people, including people with autism, find employment and stay in work.

8.3. Local authorities can also play a key role in supporting adults with autism in their area to gain employment by making sure that participation in employment is a matter considered in needs assessments, and in the exercise of their other care and support functions in respect of an individual, and that the care planning process takes account of existing or future work opportunities.

8.4. Local authorities also have a role to play in the provision or arrangement of preventative services and facilities; and in effective transition planning to ensure successful transition of young people with autism from education into employment. In their role as an employer, local authorities could set an example to other employers by becoming an autism-friendly place to work; and by actively recruiting and employing more people with autism through apprenticeships, traineeships or supported internships as mentioned in Section 3 under good practice.

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[60] Work Choice – https://www.gov.uk/work-choice and Access to Work https://www.gov.uk/access-to-work

Local Authorities must:

- Ensure that the assessment and care planning process for adult needs for care and support considers participation in employment as a key outcome, if appropriate, and looks at the ways that any such needs may be met in a way which could support adults with autism to become ‘work ready’;
- when carrying out a needs assessment, consider whether matters other than the provision of care and support could contribute to the achievement of the outcomes an adult with autism wishes to achieve in day-to-day life, and whether the adult would benefit from the provision of anything under section 2 or 4 of the Care Act (preventative services or information and advice services) ,or anything that may be available in the community, including signposting, as appropriate, to Access to Work for interview support, and to other appropriate benefits and agencies that can help people with autism to find and keep a job.
- Ensure that employment is promoted as a positive outcome for the majority of children and young people with autism who have EHC plans and that routes to employment are fully explored during the reviews of those plans from Year 9 (age 13-14) onwards and included in plans where appropriate. Information on preparing for and finding employment must be included in the local authority’s Local Offer under the Children and Families Act 2014.

It would be good practice for local authorities to work with local partners:

- To include the employment support needs of the local population of adults with autism, including those who are not eligible for care and support, in local autism plans as part of supporting their health and wellbeing, and commission relevant services;
- To consult people with autism and their representatives, whether or not they are eligible for care and support, about barriers to employment and examples of local good practice;
- To have representatives from Jobcentre Plus and local employers join the local Autism Partnership Board and encourage them to attend and play a meaningful role in setting a clear steer for improving services. Developing employment support services will help a local authority meet its prevention duties under the Care Act 2014;
- So that employment services provided under the duty to prevent, reduce or delay needs address the needs of those leaving children's services who are not eligible for adult care and support, regardless of whether they had an EHC plan;
- So that young people understand what employment is (e.g. how it will impact on their daily routine and their expectations), even if this is just basic awareness given at transition stage;
- So that the work of the local authority itself in relation to promoting employment effectively addresses the issues and needs of people with autism. Local authorities could lead by example and consider where their employment practices could be adjusted and promoted for adults with autism; and
- To play an active part in developing and promoting local autism Apprenticeship schemes by proactively engaging employers and recruiting potential apprentices with autism.

NHS bodies and NHS Foundation Trusts should:

- Seek to ensure that occupational health providers from which they commission services have sufficient understanding and knowledge (of which Section 1 of this guidance relates) of the needs of people with autism in relation to accessing occupational health matters related to gaining and maintaining employment.

Additional information on good practice supporting employment effectively

Supporting people with hidden impairments

8.5. The Hidden Impairment Toolkit offers hints and tips on how employers can better support people with associated hidden impairments such as:

- Autistic Spectrum conditions including Asperger Syndrome;
- Attention Deficit Hyperactivity Disorder;
- Dyslexia;
- Dyspraxia;
- Dyscalculia;
- speech and language impairments.

Work and supporting disabled people

8.6. The following website will be helpful to sign-post people to and may be of help to staff to be aware of https://www.gov.uk/browse/disabilities/work

Employing disabled people and people with health conditions

8.7. This guidance provides links to websites to help employers become more confident when attracting, recruiting and retaining disabled people. This guidance also provides further resources.

https://www.gov.uk/government/publications/employing-disabled-people-and-people-with-health-conditions/employing-disabled-people-and-people-with-health-conditions

Advice on helping young disabled people make the transition to work

8.8. This guidance provides links to websites that help young disabled people find and stay in work. It is aimed at young disabled people, their parents and the professionals who work with them.

https://www.gov.uk/government/publications/help-and-support-for-young-disabled-people-to-find-and-stay-in-work/help-and-support-for-young-disabled-people-to-find-and-stay-in-work.

The National Autistic Society

8.9. The National Autistic Society website has a range of employment information.

http://www.autism.org.uk/working-with/employment-services.aspx

9. Working with the criminal justice system

9.1. People with autism need access to support whether they are a victim, or witness, or are suspected of committing a crime. Local authorities, NHS bodies and Foundation Trusts can play a key role in supporting adults with autism who come into contact with the criminal justice system.

9.2. When people with autism come into contact with the criminal justice system it is often up to them, or their carer, to explain what having autism means. In some cases, it can positively change the way that police or courts view a situation. Police, probation services, courts and prisons should be supported so that they are aware of the communication challenges experienced by people with autism. NHS bodies, Foundation Trusts and local authorities should work with the criminal justice system to achieve this.

The role of Local Authorities

9.3. Wherever possible, local authority based Community Safety Partnerships (CSPs) should be used as a vehicle for bringing agencies together to develop plans to support the Autism Strategy. CSPs are an important feature of the network of partnerships that help to tackle crime, and usually work at district or unitary authority level. Five 'responsible authorities' have statutory membership. These are the local authority; police; probation; CCGs; and the fire and rescue authority.

9.4. The responsible authorities are under a statutory duty[61] to work together to:

- reduce reoffending;
- tackle crime and disorder;
- tackle anti-social behaviour;
- tackle alcohol and substance misuse; and
- tackle any other behaviour which has a negative effect on the local environment.

9.5. In addition, CSPs are free to work with any other local partners they want to. Many include representatives from the business, or the voluntary, community and social-enterprise sectors.

The role of NHS bodies and NHS Foundation Trusts

9.6. There is a need for the criminal justice system to refer people with autism for appropriate health and care support to divert them from offending, where appropriate, and prevent re-offending.

9.7. The new liaison and diversion standard service specification requires providers to identify a validated screening tool for autism acceptable to NHS England Area Team Health & Justice Commissioners. Information gained from assessments will (with the informed consent of the individual) be shared with relevant key decision makers within youth and criminal justice agencies (as appropriate), to enable them to make more informed decisions concerning the individual.

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[61] Section 108, Policing and Crime Act 2009 – http://www.legislation.gov.uk/ukpga/2009/26/section/108

9.8. This information will also assist criminal justice agencies to consider whether reasonable adjustments are required to enable individuals to effectively engage in the youth and criminal justice systems. The ability of some people with autism to make decisions and predict consequences may need to be considered when looking at informed consent.

9.9. Liaison and Diversion is an assessment and referral service. Referrals will be made to appropriate support and treatment services within the community, across a range of commissioners, depending upon the types of need identified. Some people with autism who access Liaison and Diversion services will not be eligible to have their care and support needs met by the local authority. However, these individuals may benefit from preventative, or information and advice, services that local authorities have in place.

9.10. Information about the person with autism should go with them throughout the justice process, so that if they end up in prison or under probation supervision, the prison or probation provider should be made aware of that person's needs.

9.11. In addition, victims of crime with autism, as well as those accused of offences, need to be considered in the context of the criminal justice system. The duty on local authorities, under the Care Act, to carry out an assessment of an adult's needs for care and support where it appears to them that an adult may have such needs, may, for example, be triggered by their awareness of an adult having been the victim of a crime.

Access to support in prison or other forms of detention

9.12. Local authorities have responsibilities, under the Care Act from April 2015, to assess the care and support needs of adults (including those with autism) who may have such needs in prison or other forms of detention in their areas (and to meet those needs which are eligible). NHS England is responsible for arranging the provision of health services for such prisoners and detainees. For people with autism this will include offering access to the local diagnosis pathway and access to assessment of care and support needs in advance of release from prison.

Local Authorities must:

- Under the Care Act, from April 2015, assess the care and support needs of adults (including those with autism) who may have such needs in prisons or other forms of detention in their local area, and meet those needs which are eligible;
- Work with prisons and other local authorities to ensure that individuals in custody with care and support needs have continuity of care when moving to another custodial setting or where they are being released from prison and back into the community.

It would be good practice for local authorities, in partnership with NHS bodies and NHS Foundation Trusts:

- As the Liaison and Diversion approach is rolled out, to connect with the local authority autism lead, relevant community care assessment team(s), and local preventative services with local Liaison and Diversion services.

NHS bodies and NHS Foundation Trusts should:

- Ensure that Liaison and Diversion services have in place a clear process to communicate the needs of an offender with autism to the relevant prison or probation provider;
- Ensure that in commissioning health services for persons in prison and other forms of detention
  - prisoners are able to access autism diagnosis in a timely way and;
  - healthcare, including mental health support, that takes account of the needs of people with autism.

Local Authorities, NHS bodies and NHS Foundation Trusts should:

- Seek to engage with local police forces, criminal justice agencies and prisons to the training on autism that is available in the local area;
- Consider undertaking some joint training with police forces and criminal justice services working with people with autism.

Additional information on good practice to deliver effective criminal justice services

9.13. The website of the Autism and the CJS public engagement project funded by the British Psychological Society can be found at (http://www.autismandcjs.org.uk/). It is still in the development process, and has links and lay summary literature aimed at CJS professionals.

9.14. The guidance for CJS professionals on autism (published by the National Autistic Society (NAS) and endorsed by the Association of Chief Police Officers) is available to download at http://www.autism.org.uk/%20working-with/criminal-justice/autism-a-guide-for-criminal-justice-professionals.aspx

9.15. There is also a lot of information on the NAS website on autism and the CJS http://www. autism.org.uk/working-with/criminal-justice/ criminal-justice-system-and-asds.aspx

9.16. The Care not Custody briefing paper: http://www.prisonreformtrust.org.uk/Portals/0/ Documents/care%20not%20 custody%20 coalitionlo.pdf is useful resource.

9.17. This paper outlines how the government is ensuring that people with mental health problems, learning disabilities and other support needs caught up in the criminal justice system are identified and diverted into appropriate healthcare and support services.

Appendix A: Key changes to relevant legislation and health and social care reforms since 2010

1. Since the 2010 statutory guidance there have been many changes in health and social care. Local NHS commissioning is now led by CCGs, supported nationally by NHS England. Local authorities have taken on important public health responsibilities for their local communities. The Care Act will make transformations to local care and support. There is a much stronger focus on personalised care and choice throughout health and social care with the individual more in control of their own lives. At a local level the NHS and local government now come together through Health and Wellbeing Boards to understand local health and care needs and discuss together the priorities for their local communities. For young people, there are new provisions in the Children and Families Act for special educational needs and disability support.

Health and Social Care Act 2012 and what it means for adult autism

Clinical Commissioning Groups

2. CCGs were created following amendments to the NHS legislation introduced by the Health and Social Care Act in 2012 and have become a vital part of the health service in England. When the NHS was restructured, CCGs took over certain functions from the primary care trusts, which were abolished under the new system. CCGs' functions involve, in particular, the commissioning of most NHS hospital health care, NHS community health care, NHS ambulance services, and NHS mental health services. Between them, CCGs and the newly formed NHS England commission NHS services. Sometimes CCGs share responsibilities for commissioning health services with local authorities.

NHS England

3. NHS England is the operating name of the NHS Commissioning Board, established in April 2013 as a statutory body corporate by section 1H of the National Health Service Act 2006, as amended by the Health and Social Care Act 2012. Before that, a predecessor special health authority, the NHS Commissioning Board Authority, established in October 2011, carried out certain functions in anticipation of the 2012 Act, subject to Parliament's passing that Act. NHS England oversees the budget, planning, delivery and day-to-day operation of the commissioning side of the NHS in England as set out in the Health and Social Care Act 2012, and co-commissioning with CCGs, and commissions certain services itself, such as prescribed specialised services and prison health services.

Health and Wellbeing Boards

4. Health and Wellbeing Boards were required to be established in every upper tier and unitary Local Authority in England by the Health and Social Care Act (2012) and the requirement applied from 1 April 2013. They were introduced to provide a forum for local Government, NHS commissioners and providers, Healthwatch, local communities and wider partners, to share leadership for the local health and wellbeing system. Their main purpose is to improve the strategic co-ordination of commissioning services across the NHS, social care, public health and children's service and drive improvement in the health and wellbeing of local populations and reduce health inequalities, including for people with autism, through the JSNAs; and a strategy to address these in Joint Health and Wellbeing Strategies (JHWSs). Section 116A of the Local Government and Public Involvement in Health Act 2007 requires the Local Authority and partner CCG to prepare a "joint health and wellbeing strategy" where there is a JSNA.

Joint Strategic Needs Assessments

5. The Health and Social Care Act established that JSNA functions are to be exercised by Health and Well-being Boards. Under section 194 of the 2012 Act, a Local Authority must establish a Health and Wellbeing Board, a committee of the local authorities, which should consist of a councillor, various officers for the local authority and representatives of other stakeholders. Section 116 of the Local Government and Public Involvement in Health Act 2007 as amended by the 2012 Act, provides that it is for the responsible local authority and each of its partner CCGs to prepare any joint strategic needs assessment in relation to the authority's area. By section 196 of the 2012 Act, the functions of a local authorities and its partner CCG under section 116 are to be exercised by the Health and Wellbeing Board as established by local authorities.

The Care Act 2014 and what it means for adult autism

6. The Care Act 2014 represents the most comprehensive reform of social care legislation in over 60 years, creating for the first time a single, modern statute for adult care and support. The Act puts in place requirements for local authorities to meet a person's eligible care and support needs, and to help and protect people with care and support needs, who may be at risk of abuse or neglect as a result of those needs. The provisions will take effect from April 2015. The areas of the Care Act which will be most relevant to local authorities' approach to autism are prevention, integration and co-operation (in terms of health and social care provision), information and advice, duty and powers to meet needs, safeguarding adults at risk of abuse or neglect, transition for children, and advocacy.

7. The Care Act is built around people, it:

- Creates a 'well-being principle' to underpin the care and support system. This means that people's well-being, and the outcomes which matter to them, will be at the heart of every decision that is made;
- Is a historic step for carers, putting their rights on the same footing as the people they care for, for the first time;
- Creates freedom and flexibility to encourage innovation and integration, to ensure that services are based around

people's outcomes, not structures and systems;

- Provides new focus on preventing and delaying needs for care and support, rather than only intervening at crisis point. This means services for the broader community, not just those with assessed care and support needs;
- Puts personal budgets on a legislative footing for the first time, which will be central to people planning their own care and support, and exercising control over how it is provided. This will include choice over how money available to meet their care and support needs will be managed (e.g. by direct payments);
- Will require local authorities to provide people with information and advice about the care and support system, and to promote the diversity and quality of the local care market, shaping care and support around what people want;
- Puts adult safeguarding on a statutory footing for the first time;
- Introduces a duty on local authorities to provide certain people with independent advocacy to enable them to participate actively in the assessment, care planning, review and safeguarding processes.

The Children and Families Act 2014 and what it means for adult autism

8. Part 3 of the Act (Children and Young People in England with Special Educational Needs or Disabilities) commenced on 1 September 2014. There are opportunities for improved transition which are being brought about by the Act and should be made to work for children and young people with autism.

9. The Act requires local authorities when carrying out their special educational needs and disability functions have regard to the views wishes and feelings of children, parents and young people (i.e. those over compulsory school age but below 25), including young people with autism. The Act also gives new rights to young people, including young people with autism, for example, to make SEN appeals or disability discrimination claims to the First-tier Tribunal (SEN and Disability.

10. The Act provides for greater co-ordination between, in particular, local authorities and health bodies when making provision for children and young people with special educational needs or disabilities by:

- promoting integration of educational and training provision with health and social care provision where this will promote the well-being of these children and young people;
- requiring joint commissioning between local authorities and health commissioners of provision; and
- requiring co-operation between local authorities and its partners including health bodies.

11. The Children and Families Act requires local authorities to publish details of the education, health, care and training provision available for disabled children and young people and those with SEN from their areas. The Act sets out that parents, children and young people must be consulted about the preparation and review of this Local Offer. Under the associated Regulations when preparing and reviewing the "local offer" the local authority must also consult the NHS Commissioning Board, any relevant CCGs, NHS Trust or NHS foundation Trust, local Health Board and Health and Wellbeing

Board i.e. they must consult relevant NHS bodies.

12. Local authorities have duties to, where necessary, to carry out Education, Health and Care (EHC) assessments of children and young people and draw up Education, Health and Care plans setting out the provision for those children and young people. Local authorities have a duty to arrange the special educational provision set out in the plan and the responsible health commissioning body to arrange the health provision.

13. For children and young people with SEN but without EHC plans the new Special Educational Needs and Disability Code of Practice: 0–25 years gives improved guidance on identification of needs. The Code gives advice on four broad areas of need – communication and interaction; cognition and learning; social, emotional and mental health difficulties; and sensory and/or physical needs. The Code makes clear that a child or young person with an autistic spectrum disorder could have needs across all these four areas and that a detailed assessment should ensure that the full range of a child's needs are identified. The Code sets out a graduated approach to meeting children's difficulties beginning with the provision of high-quality teaching targeted at a child's area of weakness. If this is unsuccessful then there should be a process of SEN support where needs are assessed, interventions planned, implemented and reviewed with successive rounds of this process if necessary.

14. The Act and the Code make clear that there needs to be planning to achieve long-term outcomes for all children and young people with SEN, including employment outcomes. The Code includes a new chapter on Preparing for Adulthood which encourages professionals to aim high for children and young people with SEND and reminds schools and colleges of their duties and responsibilities to provide careers advice to children and young people and advises them that they should raise the career aspirations of their students with SEN and broaden their employment horizons. The Code includes guidance on effective pathways to employment for these young people including apprenticeships, traineeships and supported internships.

Appendix B: *Think Autism*: an update to the strategy for adults with autism in England

1. On 2nd April 2014, in line with duties under the Autism Act 2009, and following the 2013 review led by the Department of Health into progress on the 2010 Adult Autism Strategy *Fulfilling and Rewarding Lives,* the Government published *Think Autism*, an update to the 2010 strategy.

The update was published for three reasons:

(i) To reflect what people told us during the Review of the 2010 strategy that was undertaken in 2013/14 in line with requirements under the Autism Act;

(ii) To reflect progress that has been made since 2010 and commitments that have been delivered;

(iii) To take account of changes in public services and new organisations.

2. *Think Autism* sets out fifteen priority challenges for action (see below) by people with autism, carers, professionals and others who work with people with autism. It also has a more focus on building communities that are more aware of and accessible to the needs of people with autism, on promoting innovative local ideas, services or projects that can help people in their communities and on how advice and information on services can be joined up better for people.

An equal part of my local community

1. I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism.
2. I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others.
3. I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low-level support.
4. I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism.
5. I want to be safe in my community and free from the risk of discrimination, hate crime and abuse.
6. I want to be seen as me and for my gender, sexual orientation and race to be taken into account.

The right support at the right time during my lifetime

7. I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.
8. I want autism to be included in local strategic needs assessments so that person-centred local health, care and support services, based on good information about local needs, is available for people with autism.

9. I want staff in health and social care services to understand that I have autism and how this affects me.
10. I want to know that my family can get help and support when they need it.
11. I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies.
12. I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging.
13. If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.

Developing my skills and independence and working to the best of my ability

14. I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible.
15. I want support to get a job and support from my employer to help me keep it.

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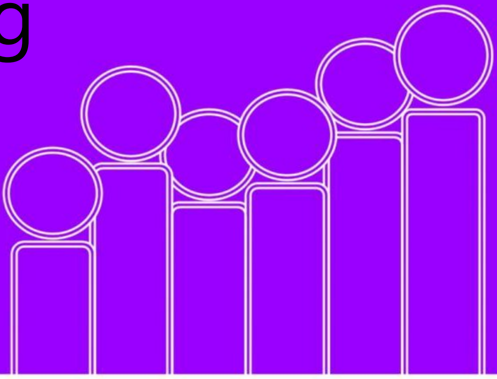
Improving Health and Lives:
Learning Disabilities Observatory

How people with learning disabilities die

Gyles Glover and Muhammad Ayub



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How people with learning disabilities die

Gyles Glover
Muhammad Ayub

IHAL 2010-06

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Acknowlegements:

The authors are grateful to Stewart Einfeld of the University of Sydney and to our colleague Eric Emerson for their assistance with this work.

Contents

Summary

Using information from death certificates we studied the ages and causes of death for people with learning disabilities, or conditions which can cause learning disabilities, who died in England between 2004 and 2008.

Other studies have shown that only about four out of ten death certificates for people with learning disabilities record this problem. Numerically, our figures were roughly in line with this, but we found some causes of learning disabilities, for example Down's syndrome were better reported than others. Fragile-X syndrome and autistic spectrum conditions were particularly poorly reported.

Age at death

All groups with definite or possible learning disabilities died younger than people without. People with learning disabilities, but no physical condition reported as a cause lived longest but the age by which half of these had died was 15 years younger than for people without learning disabilities. People with Down's syndrome commonly die in their fifties and sixties, and people with hydrocephalus / spina bifida in their thirties and forties.

Causes of death

When we looked at what people died of, many well know associations (like Down's syndrome with thyroid or hole-in-the-heart problems) were clear.

Two, possibly preventable causes stood out as particularly important because they were common and affected most groups of people with learning disabilities. They were lung problems caused by solids or liquids going down the wrong way (14% of deaths where a condition associated with learning disabilities was reported), and epilepsy or convulsions (13%).

Just over 5% of people with hydrocephalus / spina-bifida died with pressure sores; in three quarters of cases this had led to an infection of the blood.

Services looking after people with learning disabilities should pay particular attention to these problems.

Introduction

The Learning Disabilities Observatory (IHaL) was set up as a result of the Inquiry into the deaths of six people with learning disabilities. A big part of our job is to investigate the health of, and health care health for people with learning disabilities, using things that are counted in official or NHS statistics. The earliest health statistics were counts of the ways people died. So this is an obvious and important subject for an early report.

For this report we looked at death certificates, the official records of all deaths that happened in England between 2004 and 2008, the most recent five years for which data were available at the time we started our work. We asked three questions:

1. How many people could we tell had learning disabilities from their death certificates?
2. Compared to other people, how old were they when they died? and
3. What did they die of?

The point of this work was to ask:

1. Are there are any causes of death that are particularly important for any groups of people with learning disabilities? and
2. Could we count these regularly in any way to see whether things are getting better or worse and whether they are better or worse in some places than others?

Background

What is a death certificate?

When a person dies, a doctor who has been looking after them has to fill in a special form saying when they died and what they died of. Their relatives take this to the Registrar at the Town Hall and give some more details including where they lived, and how old they were. The Registrar then gives them a Death Certificate which proves the person is dead and gives the causes.

Has anyone done this before?

We couldn't find any reports, based on death certificate data for the whole of England, that were mainly about how people with learning disabilities die. We found two research studies about deaths of people on local learning disability case registers in England that looked at their death certificates.

Central London

Professor Sheila Hollins and her colleagues looked at all the people on registers of learning disability service users in two parts of central London, who died between 1982 to 1990. They looked at their death certificates but were also able to use other information about them from the registers.[2]

Out of just over 2,000 people on the registers, 270 (13.3%) died in the period. Learning disability, or a cause of it, was mentioned on the death certificates of just under half of those who died. Overall death rates were 10 times higher than the local population in one area and 18 times higher in the other. People with learning disabilities died at much younger ages, more than half before age 65. The commonest cause of death was pneumonia. This was the immediate cause of death for 45% of people. Epilepsy was recorded on the death certificate for 27%. People with cerebral palsy, incontinence, mobility problems and people who lived in hospital died younger.

Leicestershire

Dr Freya Tyrer and Dr Cath McGrother worked with the learning disability service user register for Leicestershire.[1] They looked at the causes of death, and the death certificates for the 503 people on the register who died between 2003 and 2006. Just under half (41%) of the death certificates said that the person had a learning disability or a condition that might cause this. Just under half (45%) the people for whom there was some mention had Down's syndrome. Learning disabilities or developmental disorders were mentioned in 30 cases (6%). The most common causes of death were

- respiratory diseases: 131 deaths (26%), five times more common than in the general population, and
- heart or circulatory diseases: 123 deaths (24%) just under twice (1.75 times) as common as in the general population.

We found one study of deaths of people with Down's syndrome, from America, that used only death certificates. This was particularly interesting as the authors had exactly the same type of data we did. Studies of patterns of death in groups of people usually depend on knowing how many people there are in the group overall as well as how many of them die. Sheila Hollins and Freya Tyrer knew this from the case registers they used. But for people with learning disabilities, this method can only be used for small areas with case registers. This means the numbers of deaths that can be studied are also quite small. Quanhe Yang studied the whole of the United States over fifteen years.

People with Down’s Syndrome in the United States of America

Quanhe Yang and his colleagues in the United States used just death certificates to see whether there had been changes in the life expectancy of people with Down’s syndrome. First they looked at the ages people died. The mid-point in the ages at which people died (called the median age at death) was 25 in 1983, but had nearly doubled to 49 by 1997. Death certificates for people with Down’s syndrome were more likely include heart defects, dementia, thyroid deficiency and leukaemia as causes than certificates for other people. Almost all other types of cancer were mentioned less commonly. They used a method called Standardised Mortality Odds Ratios (SMORs). We use both of these methods in this study.[6]

How we worked

Death certificates can show that the person had learning disabilities in two ways. They can simply say they did, or they can say they had a condition, like Down's syndrome, that causes learning disabilities. Down's syndrome nearly always causes learning disabilities. Some other conditions, like cerebral palsy, often do, but not always.

We started by making a list of all the conditions that can cause learning disabilities. Then we divided these into those that usually cause learning disabilities, those that sometimes do (more than 1 in 7 - 15%), those that only rarely do (less than 1 in 7 – 15%), and degenerative conditions causing learning disabilities and inevitable early death. For common conditions research studies tell us how many people with the conditions are affected this way, but for rare conditions there is less information. We compared our list to a similar list made by researchers at the NHS Information Centre for looking at care by GPs,[15] and we asked two experts to advise us. Our full list is shown in Appendix Table 1.

We obtained the computerised file of records of all the deaths in England from 2004 to 2008 from the Office for National Statistics. This gives peoples sex, dates of birth and death, age at death, up to eight causes for their death and says where they normally lived.

We started by looking at how many people who died had each condition on our list. We decided that for it would be possible to report individually on conditions where 100 or more people had died. We grouped other people on the basis of whether their condition usually, sometimes or rarely causes learning disabilities, or is a degenerative condition. We looked at two further groups, those where the death certificate said they had learning disabilities but gave no condition causing it, and all the rest where there was no evidence of learning disabilities.

Statistics

We did the analysis using Microsoft Access, Excel and STATA v10. We drew the maps using Arc-Info.

Because we did not have accurate figures for the population in each of the groups with learning disabilities we studied, we analysed the proportion of deaths from different causes. We compared these using standardised mortality odds ratios (SMORs), an approximation of the Standardised Mortality Ratio designed for use with this type of data.[6] We explain this technique alongside the findings from it.

We calculated confidence intervals for proportions using the Wilson method (which is appropriate for the types of very small proportion characteristic of this type of data). Confidence intervals for SMORs were calculated using Byar's method for confidence intervals for individual numerical observations, as recommended in the APHO guide to statistical methods for epidemiological data.[9] We tested differences in distributional patterns using Chi Square tests.

What we found

Numbers of deaths:

All Deaths in England, 2004 to 2008 :	**2,362,095**
Deaths of people with:	
Degenerative conditions causing learning disabilities:	**367**
Down's syndrome:	**2,163**
Cerebral Palsy:	**1,868***
Hydrocephalus / Spina bifida:	**523***
Neurofibromatosis:	**234***
Microcephaly:	**154***
Deaths of people with other conditions:	
Usually associated with learning disabilities:	**618**
Sometimes associated with learning disabilities:	**420***
Rarely associated with learning disabilities:	**246***
Deaths of people with	
Learning disability but no associated condition:	**887**

* Only some of these people will have had learning disabilities

Overall numbers

The headline box above shows the total number of deaths in the five years and the numbers of people who died in the groups we can report on. 984 death certificates stated that the person had learning disabilities, but many more said the person had a condition which either can or usually does cause this. Five specific conditions were reported for at least a hundred people who died. One of these, Down's syndrome, is nearly always associated with learning disabilities. The numbers with each one of the conditions we looked at are shown in Appendix Table 1

Table 1, on the next page, shows the numbers and the numbers per thousand deaths. For each condition it shows how often the death certificate also said the person had learning disabilities. This shows that generally when a condition, like Down's syndrome is reported, the certifying doctor will not also say the person had learning disabilities, and when learning disabilities is reported as such, usually no condition causing it is reported.

Table 1. Overall numbers of deaths with conditions associated with learning disabilities (LD), and numbers and proportions reported as having learning disabilities (LD).

Condition	Deaths	Per 100k deaths	Number of these identified as having learning disabilities
Degenerative conditions associated with LD	376	15.9	2
Down's Syndrome	2163	91.6	16
Cerebral palsy	1868	79.1	41
Hydrocephalus / Spina bifida	523	22.1	3
Neurofibromatosis	234	9.9	1
Microcephaly	154	6.5	13
More than one of these conditions	*53*	2.2	2
Other conditions usually associated with LD	618	26.2	2
Other conditions sometimes associated with LD	420	17.8	14
Other conditions rarely associated with LD	246	10.4	3
No medical condition associated with LD	2,355,546	99,722.7	887
All deaths	2,362,095		

How complete were our figures?

We wanted to know how close the death certificates we identified came to the number of people we know are likely to have had learning disabilities from other sources. The box shows how we did this.

How we estimated the total number of people with learning disabilities in the death statistics.

We made a rough estimate of the number of people these figures suggested actually had learning disabilities. This was based on research studies where we could find them and expert opinion where we could not. We assumed that everyone with the degenerative conditions, Down's syndrome, the other conditions usually associated, or whose death certificates stated they did, had learning disabilities. In addition to this we estimated that 44% of people with cerebral palsy,[4] 38% of people with hydrocephalus / spina-bifida,[5] 8.5% of people with neurofibromatosis,[8] 90% of people with microcephaly, 50% of those with conditions sometimes associated and 5% of those with conditions rarely associated also did. Where people had more than one condition we combined the probabilities.

This suggested that overall, a total of 5,430 of the people whose death certificates we knew about had learning disabilities. This is 2.3 per 1000. This is about half of the most recent estimate of the number of adults who have learning disabilities at any time from General Practitioner records, [16] or that Eric Emerson and Chris Hatton estimated are likely to have severe or profound learning disability.[17] It is about one tenth of the number children identified as having moderate or more severe learning disabilities from the latest school census.

These estimates are also similar to the findings of Sheila Hollins and by Freya Tyrer. Both of them found that less than half of the people with learning disabilities they knew had died, had their learning disability, or the condition causing it reported on their death certificate.

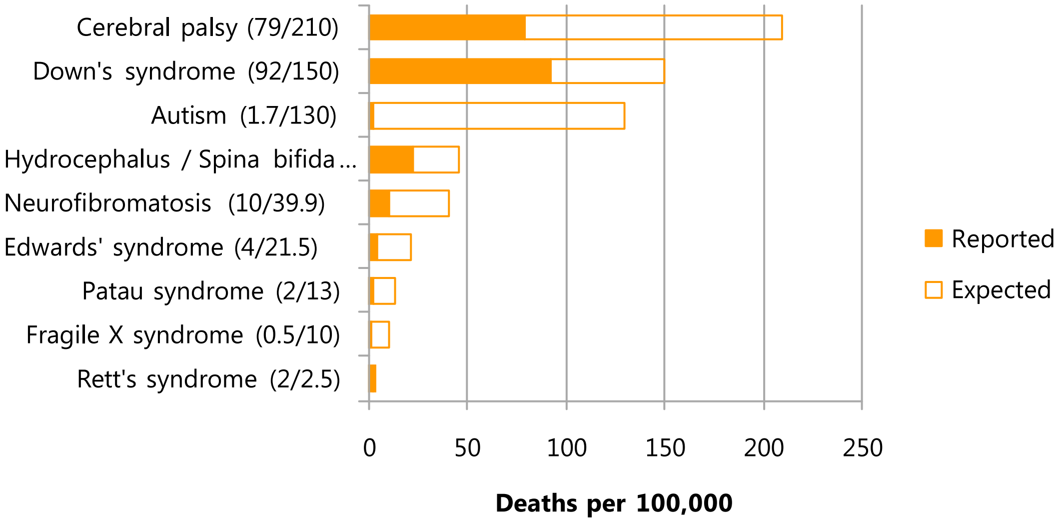
But these estimates are not exactly comparable as they take snapshots of the number alive at a point in time. Our figures will give more prominence to conditions where people die young and less to conditions where people reach older ages.

So we looked in more detail at conditions where we had better evidence. Where possible we compared the numbers of individuals we could identify with studies of how many children born have each of the various conditions. This is a more appropriate comparison. Chart 1 shows how many deaths per 100,000 were reported as having each condition, and the estimated number we would expect based on research studies. The text box below gives details of the research studies we used.

Down's syndrome and Hydrocephalus were reported about half as often as we would expect, cerebral palsy and neurofibromatosis rather less than this. Of the rarer conditions, Rett's syndrome reports appeared to be well reported, but numbers of deaths with Pattau's or

Edwards' syndromes were under one fifth of those expected. Autism and Fragile X syndrome were particularly poorly reported.

Chart 1. Comparing reported and expected deaths per 100,000 population for the more common conditions.



How we estimated the expected number of death with each condition

Down's Syndrome: Found 92 per 100k deaths - expected 150. Principal estimate from a statistical model based on seven English registers (15 years) and two Australian regional registers (23 years), to 2003/4.[3] Adjusted down (from 170) on the basis of a study reviewing studies of 10 year survival for infants born with Down's Syndrome; this rose from 50% in the 1950s and 1960s to 80% in 1990s, suggesting smaller proportions of earlier birth cohorts would have survived childhood.

Cerebral Palsy: Found 79 per 100k deaths - expected 210. Study based on registers covering births in six English counties and Scotland, 1984 to 1989.[4]

Hydrocephalus / Spina-bifida: Found 22 per 100k deaths - expected 45. The incidence of infantile hydrocephalus was reported as 53 per 100k in Sweden from 1967 to 1982.[5] English congenital anomaly registers show, for the South West an average of 33 per 100k live births between 2002 and 2008; register for the North East and Cumbria and for Oxfordshire, Berkshire and Buckinghamshire show comparable figures.[7]

Neurofibromatosis: Found 10 per 100k deaths - expected 40 for types 1 and 2 neurofibromatosis combined. Manchester study based on North West Family Genetic Register and North West Cancer Intelligence Service between 1974 and 1993[10]

Fragile X syndrome: Found 0.5 per 100k deaths – expected 10. [11]

Autism spectrum conditions: Found 1.7 per 100k deaths – expected 130 [12]

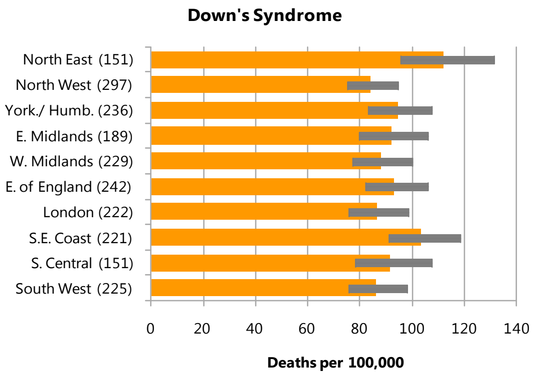
Rare conditions usually causing learning disabilities

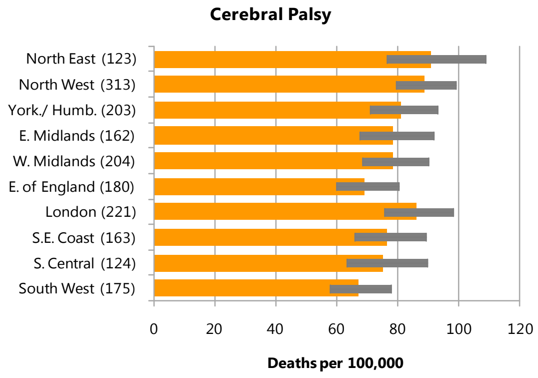
Patau's syndrome Found 2 per 100k deaths – expected 13 and **Edwards' syndrome** found 4 per 100k deaths – expected 21.5 (statistical model based on seven English registers (15 years) and two Australian regional registers (23 years), to 2003/4 [3]

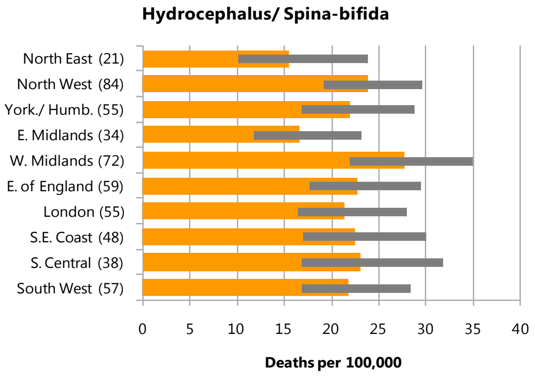
Do the numbers vary around the country?

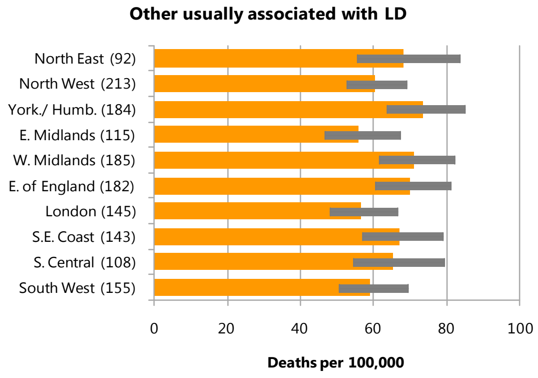
The next set of charts (chart 2) show how the numbers of deaths varied around England. We used the ten large NHS administrative zones - 'Strategic Health Authority' areas. The charts show, for each strategic health authority area, the number (per 100,000 deaths) of people who died in the four largest of our categories.

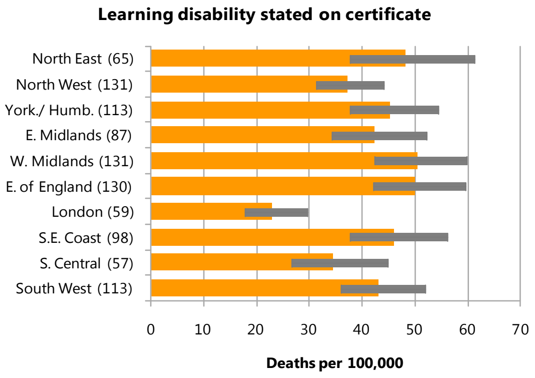
Chart 2. Variations in rates for conditions between Strategic Health Authorities


Down's Syndrome


Cerebral Palsy


Hydrocephalus/ Spina-bifida


Other usually associated with LD


Learning disability stated on certificate

The charts show how the exact numbers, per 100,000 deaths, vary around the country (the yellow bars). However, in most cases the actual numbers of deaths are fairly small and often the differences were no more than could occur on the basis of random fluctuation. To show where the differences are reliable and where they are not, the charts also include grey bars on each column. These are called confidence intervals and they show the range within which we can be confident the true figure lies. Where these don't overlap for two areas, we can be confident they are really different. Confidence intervals are explained in the box.

Confidence Intervals

We have looked at the numbers of people who died with various conditions in the five year from 2004 to 2008. If we had started a year earlier, or a year later, the numbers would probably have been similar but not exactly the same. If two places had 80 and 100 deaths in our figures, one or two more or less deaths in either place would not make much difference to the conclusions. But if one had 8 deaths and the other 10, then while our figures would show the same pattern of one greater than the other, one more death in one place and one fewer in the other would make them equal. Two more and less would change the order.

Statistical 'confidence intervals' are worked out to take the overall size of the numbers into account. They show the range within which we could be confident, 19 times out of 20, that the next, or previous set of observations would lie assuming nothing is changing.

How old were people when they died?

Ages by which half of deaths occurred

People with specific conditions:	
Down's syndrome	**56**
Cerebral palsy	**35**
Hydrocephalus / spina bifida	**38**
Microcephaly	**10**
Neurofibromatosis	**53**
People with other conditions associated with learning disabilities	
Other conditions **usually** causing learning disabilities	**8**
People with conditions **sometimes** causing learning disabilities	**23**
People with conditions **rarely** causing learning disabilities	**50**
People with **degenerative** conditions	**12**
People with **learning disabilities but no specified condition**	**65**
People with **no learning disabilities**	**80**

People who have learning disabilities die at younger ages than people who do not. The easiest way to show this is to identify the age by which a proportion of deaths has occurred. The obvious proportion to choose is half. Half of the deaths of people who do not have a learning disability happen at or below the age of 80. As the headline box above shows, the longest lived of the groups with learning disabilities we studied was those who were reported to have learning disabilities but with no medical condition causing it specified. Half of their deaths happened by age 65. People with Down's syndrome had the next highest age at death, with half of deaths happening by the age of 56. Other groups died younger. Half of people with cerebral palsy or hydrocephalus / spina-bifida died by their mid thirties. People with microcephaly died particularly young.

The table below gives two more sorts of detail. First it also shows the ages by which a quarter and three quarters of the deaths had occurred. This shows that deaths of people with Down's syndrome are much more closely bunched in age than deaths with some other conditions. Second, the table shows the confidence intervals for each figure. These show that the estimates are less precise where there are fewer deaths.

Table 2. Ages by which a quarter, half and three quarters of deaths had occurred, for people with learning disabilities or conditions associated with learning disabilities (LD), 2004 to 2008. Comparable ages for people without learning disabilities are shown in the bottom row.

Condition group	Deaths	Quarter	Half	Three quarters
Down's Syndrome	2,163	49 (48 to 50)	56 (56 to 57)	61 (61 to 61)
Cerebral Palsy	1,868	15 (14 to 16)	35 (32 to 37)	58 (56 to 59)
Hydrocephalus / spina bifida.	523	26 (23 to 31)	38 (37 to 40)	49 (46.1 to 53.9)
Microcephaly	154	3 (2 to 4)	10 (7 to 11)	28 (19.2 to 37.0)
Neurofibromatosis	234	33 (29.0 to 37.2)	53 (46.0 to 57.5)	71 (67.8 to 74.0)
Others Usually associated with LD	618	2 (2 to 3)	8 (6.0 to 10.9)	39 (33.7 to 44.0)
Others Sometimes associated with LD	420	5 (4 to 7)	23 (19 to 27)	41 (39 to 45)
Others Rarely associated with LD	246	34 (28.9 to 37.0)	50 (46.1 to 53.0)	67 (62 to 71)
Degenerative conditions associated with LD	376	6 (4 to 7)	12 (11 to 14)	28 (22.0 to 34.7)
LD but no condition specified	887	52 (50.0 to 53.8)	65 (63.8 to 66.0)	77 (75 to 78)
No learning disability	2,354,659	70 (70 to 70)	80 (80 to 80)	87 (87 to 87)

On the next two pages we show the pattern of ages at which people died in more detail. The lines on the graphs show the proportion of deaths that happen at each age-group or older, for each group of people with disabilities, and for those without. There are separate graphs for males and females.

The thick black lines in the graphs show the pattern for people without learning disabilities. Very few of these die before the age of 30. After this the rate of death increases in each age group, but only a quarter of deaths happen below the age of 70. In the groups with disabilities, the line closest to this is for people with learning disabilities, but no condition causing it identified. However a quarter of deaths in this group have happened by age 52, and half by age 65. Only a little over one in twenty deaths for this group is at ages older than 84, compared with nearly a quarter of deaths for people who do not have learning disabilities.

Two of the lines, for Down’s syndrome and for hydrocephalus / spina-bifida, show a period of low death rates in young adult life, followed by a sharp turn, indicating a high proportion of deaths occurring at a particular age group. For Down’s syndrome the age band is between 50 and 65; for people with hydrocephalus it is between 30 and 45. Deaths of people with neurofibromatosis, cerebral palsy and other conditions sometimes or rarely associated with learning disabilities are spread more evenly across the age ranges. Deaths happen at much younger ages for people who have microcephaly, the degenerative conditions, the other conditions usually associated with learning disabilities or more than one of the specific conditions mentioned. The patterns are similar for males and females.

Chart 3. Pattern of ages at death for males, grouped by whether or not they have learning disabilities or associated conditions

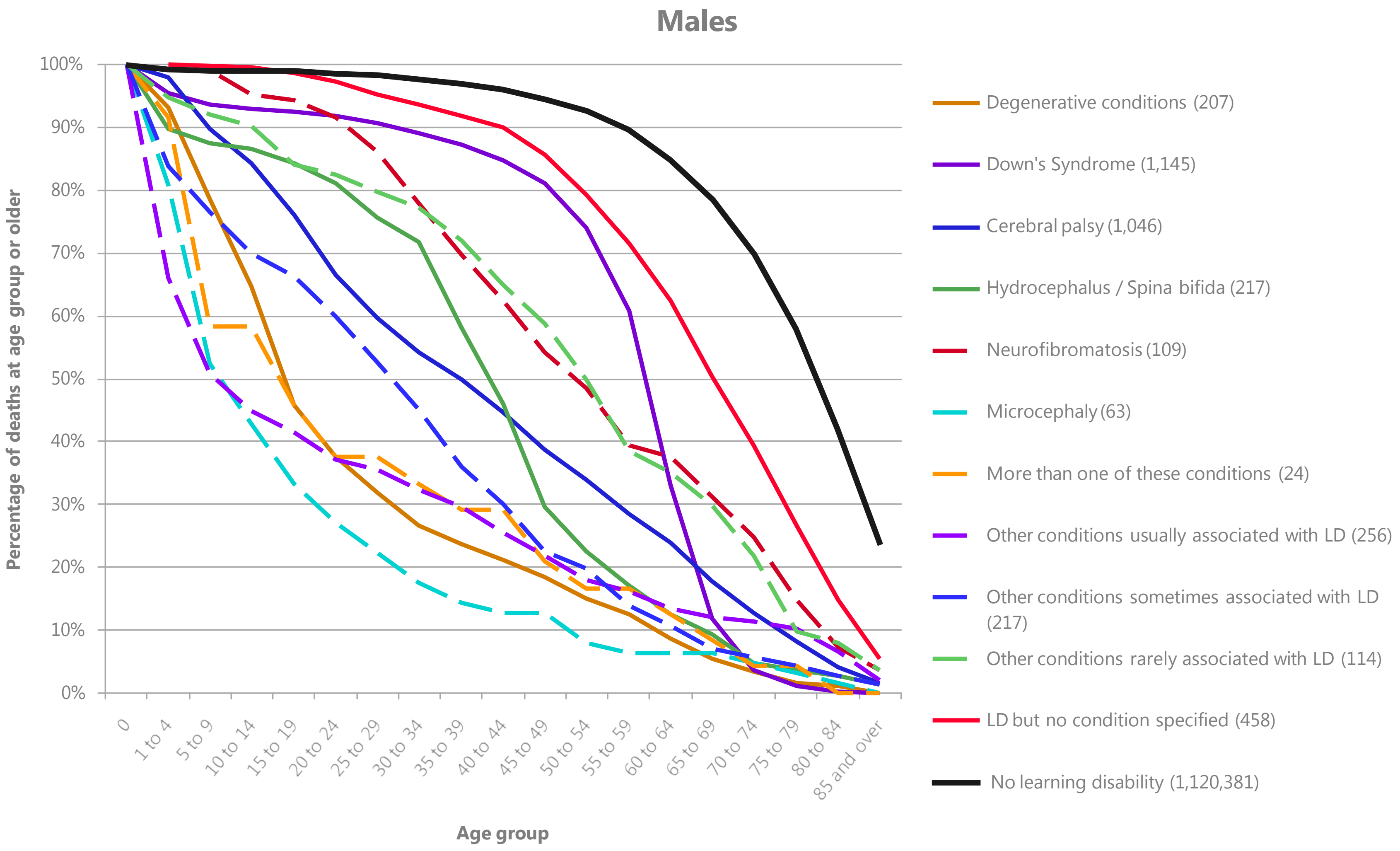
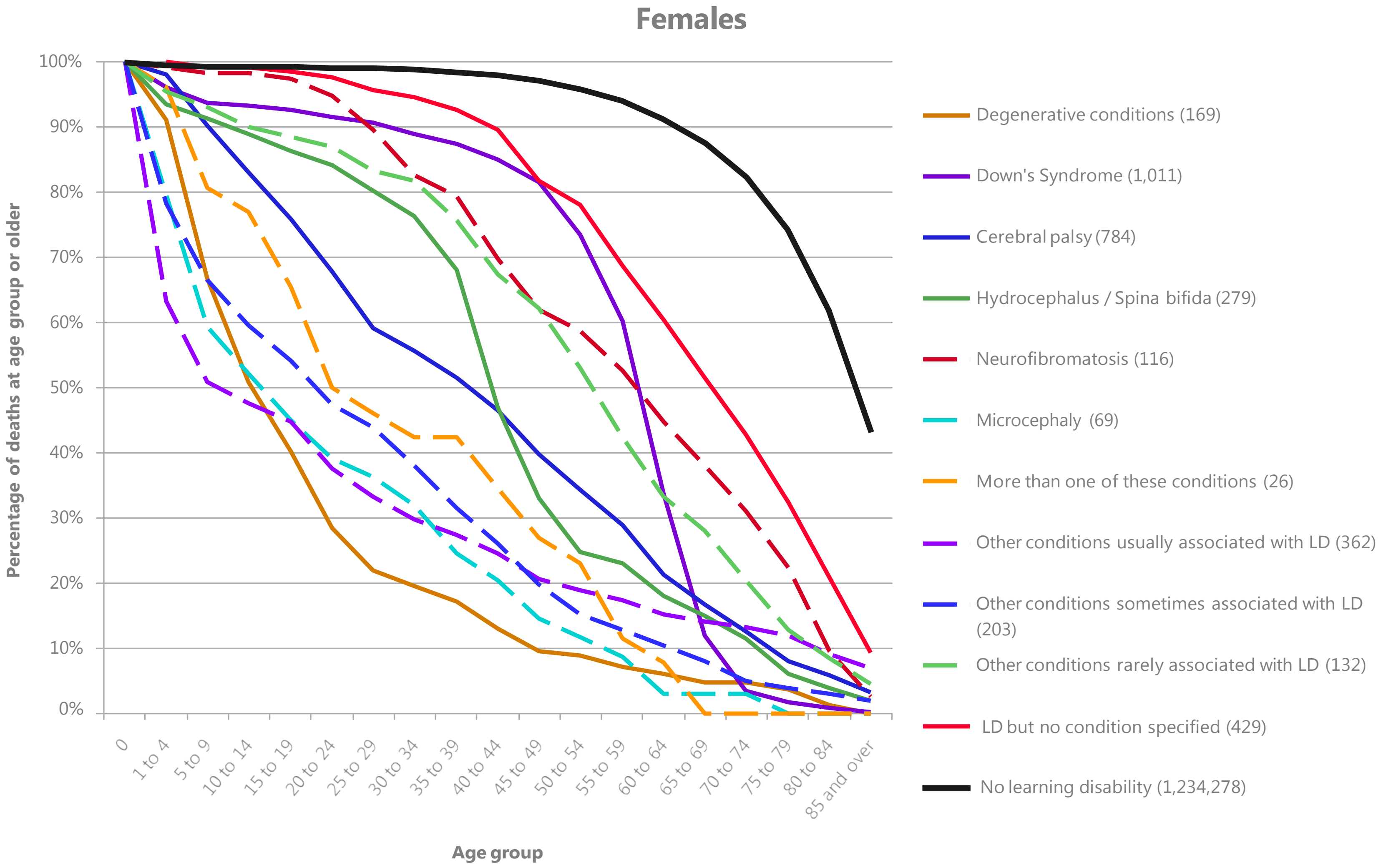


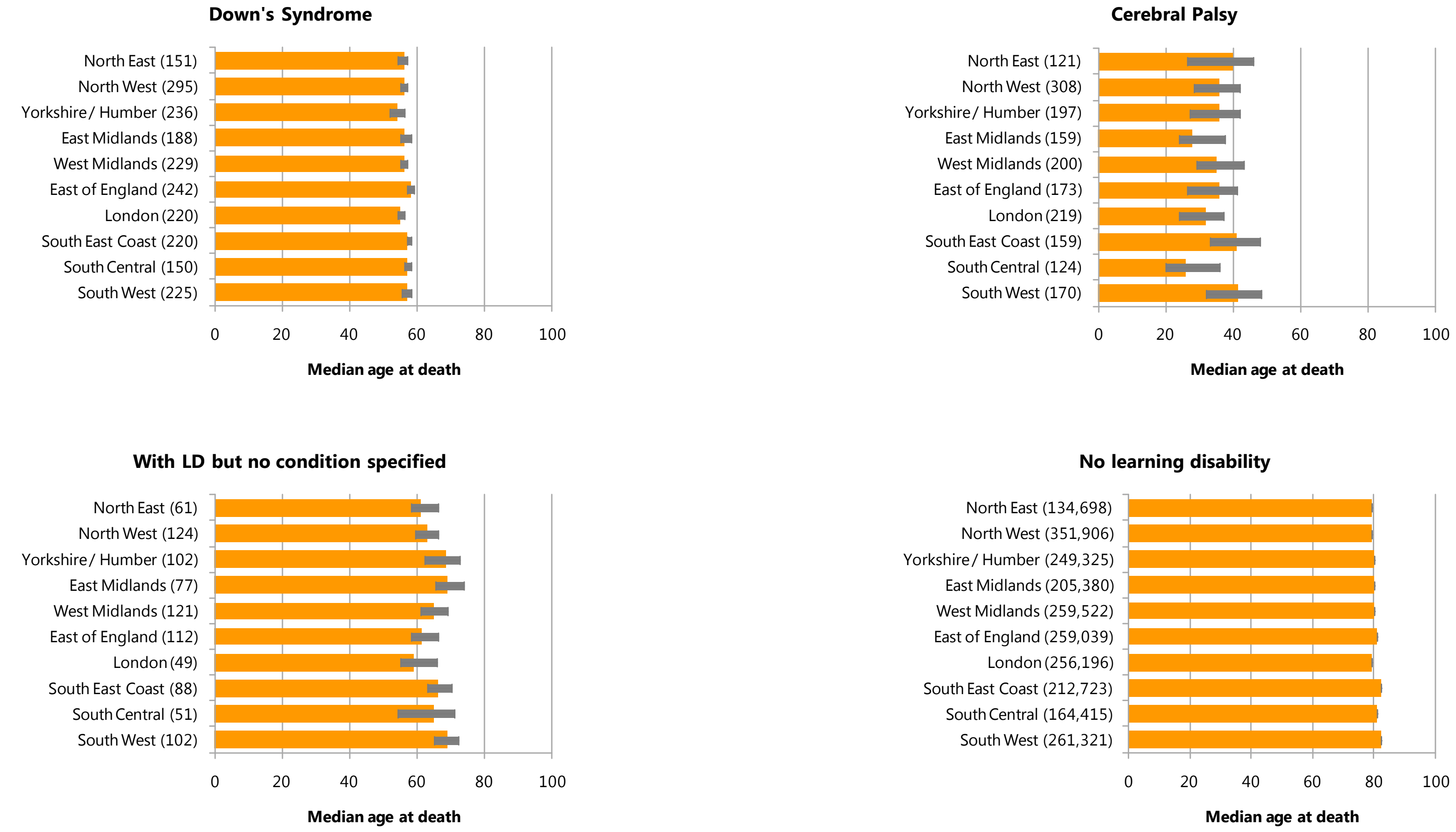
Chart 4. Pattern of ages at death for females, grouped by whether or not they have learning disabilities or associated conditions



Improving Health and Lives: Learning Disabilities Observatory

The charts on the following page show the age by which half have died, for each strategic health authority area, for the three most common groups. Even for the groups, where numbers are relatively large, any difference could be the result of random fluctuation. We have not presented this analysis for the groups with smaller numbers as it would not be reliable. We also looked at whether this value was changing over time. Only one of the conditions or condition groups we studied, hydrocephalus / spina-bifida, showed a significant trend. For people with this condition, the age by which half of the deaths had occurred, rose, in the five years, from 36 to 41.

Chart 5. Age at death – variation between strategic health authorities for common conditions



The median age at death is the age by which half the people in a group have died.

What did people with learning disabilities die from?

Death certificates can give up to eight different causes for each death. People commonly die of one type of illness (for example pneumonia) as a result of having another (for example some type of cancer). We looked first at the illnesses that were given as the cause people were reported actually to have died of (called the 'immediate cause of death'), and second at illnesses that were reported as giving rise to this.

Table 3 shows the top ten immediate causes of death for people with learning disabilities, or any condition possibly associated with it, compared to the top ten causes for all other people. People with learning disabilities are most likely to die from a respiratory illness – twice as many do as among people without learning disabilities. Heart and circulation problems, the causes that kill the largest numbers of other people, are in second place, killing only half the proportion of people with learning disabilities. Infectious and nervous diseases are more important, and cancers appear to be much less important. In both groups, for about one person in twenty the immediate cause of death is given as a sign or symptom, rather than an actual illness. For both groups the commonest three signs in this category are age-related physical debility, stopping breathing (respiratory arrest) and the very general description 'malaise and fatigue'.

Table 3. Top ten causes of death: people with any condition associated with learning disabilities compared with people without.

	Any condition associated with learning disabilities		**No condition associated with learning disabilities**	
1	Respiratory diseases	3,866 (52.0%)	Circulatory diseases	681,126 (28.9%)
2	Circulatory diseases	898 (12.1%)	Respiratory diseases	602,880 (25.6%)
3	Infectious and parasitic diseases	459 (6.2%)	Cancers and other growths	518,150 (22.0%)
4	Nervous system diseases	393 (5.3%)	Other signs and symptoms	163,301 (6.9%)
5	Other signs and symptoms	332 (4.5%)	Infectious and parasitic diseases	103,472 (4.4%)
6	Congenital and chromosomal conditions	301 (4.0%)	Digestive system diseases	94,485 (4.0%)
7	Cancers and other growths	284 (3.8%)	Injury and poisoning	63,809 (2.7%)
8	Genito-urinary diseases	202 (2.7%)	Genito-urinary diseases	47,733 (2.0%)
9	Injury and poisoning	197 (2.6%)	Nervous system diseases	30,676 (1.3%)
10	Digestive system diseases	191 (2.6%)	Mental and behavioural disorders	23,167 (1.0%)

The top immediate causes of death vary with age. In appendix tables 2 at the end of this report we show the five most common immediate causes of death in ten year age bands for each of the groups of people with learning disabilities or conditions possibly associated.

Causes are only included if they involved at least five deaths in the five years covered. Respiratory illnesses are the most common cause for most groups at most ages.

In one case, people with neurofibromatosis, the most common immediate cause of death at most ages (cancers and other growths) is directly related to the condition possibly causing learning disabilities. Nervous system causes, are commonly given as the immediate cause of death for people with cerebral palsy. In about two thirds of cases, this is because their cerebral palsy is being reported as the immediate cause of their death, though epilepsy is also important for this group. By far the most commonly reported type of infectious illness for people in the groups with learning disabilities or possibly related conditions is septicaemia, (infection of the blood).

Underlying causes of death

Some immediate causes of death, particularly pneumonia or septicaemia, commonly arise as a result of other underlying physical illnesses. We looked at all the physical illnesses listed as causes for deaths and calculated which were unusually common, or unusually uncommon, in people with learning disabilities or possibly associated conditions. We did this using a method called Standardised Mortality Odds Ratios. This is explained in the box.

Standardised Mortality Odds Ratios (SMORs)

Normally, to see if people with a condition, like Down's syndrome die more from a particular illness, for example a cardiac septal defect (a hole in the heart), we would divide the number of people with Down's syndrome who die of this by the total number with Down's syndrome and compare the result to the same calculation done for people who do not have Down's syndrome. Unfortunately we can't do this, because we don't have precise numbers for how many people have each of the conditions associated with learning disabilities we look at in this report. But we can ask the question the other way around.

In the five years we studied, a total of 160 people with Down's syndrome and 880 others died at least partly from cardiac septal defects (CSDs) while 2,003 people with Down's syndrome and 2,353,779 people died from other causes. This means that the odds of having Down's syndrome for people who died with a CSD were 1:6 (160:880). For people dying of other causes the odds of having Down's syndrome were 1:1,175. The ratio of these 'odds' (1/6 divided by 1/1,175) was 214, meaning that someone dying of CSD was about 200 times more likely to have Downs syndrome than someone dying of any other cause.

In this case, doing the calculation for everyone all together overstates the association. This is because people die of different causes at different ages and people with Down's syndrome die younger than other people. Patterns of causes of death are also different for males and females. 'Standardising' the calculation for age and sex involves doing it separately for different age and sex groups to allow for this. We worked in 34 separate groups (17 five-year age bands for the each of the sexes).

Table 4 shows conditions that are more common in one or more of the groups with learning disabilities. A single cross indicates that one of the groups we studied was more than twice as likely to die of a cause, two crosses ten times, three crosses fifty times. A number of well-known risks are seen. People with Down's syndrome are particularly likely to die from causes related to thyroid deficiency, dementia, or heart abnormalities. People with hydrocephalus commonly have pressure sores or urinary disorders, probably explaining why this group is also unusually likely to die with septicemia. Scoliosis (curvature of the spine) is commonly given as a cause for people with cerebral palsy, hydrocephalus or learning disabilities with no causal condition identified. This last group, along with people with microcephaly are unusually likely to be reported to have lack of normal development as a cause of death.

Some causes of death are less commonly recorded on death certificates for people with learning disabilities or conditions causing this. Table 5 sets these out. It is possible that that people with the various conditions causing learning disabilities are actually less likely to have these. But another, simpler explanation is that when people die of illnesses not known to be linked to any sort of learning disabilities, doctors simply don't report the persons learning disabilities on their death certificate. This would fit in with the fact that the total number of people we were able to identify was around half the number GPs report they are looking after. Bearing in mind this possibility, we were cautious in setting up this table. The green tick means that people in the relevant learning disability group were less than half as likely to die with the condition.

Some of the illnesses seen less commonly in people with learning disabilities (notably cancers) are illnesses that characteristically affect older people. Because people with learning disabilities die younger, they would be less likely to get these. However the way we have calculated the strength of association between dying of a condition and having learning disabilities should allow for this.

There is one other slightly confusing thing about this table. There are more ticks for people with Down's syndrome, cerebral palsy and people with learning disabilities but no cause mentioned than for other groups. This is partly because the numbers of people in these groups were larger. For less common causes of death, it is less surprising to find no deaths out of a hundred than no deaths out of a thousand.

Table 4. Conditions more commonly associated with deaths for people with learning disabilities.

Condition	Down's syndrome	Cerebral Palsy	Hydrocephalus / Spina-bifida	Neurofibromatosis	Microcephaly	Other conditions usually associated with LD	Other conditions sometimes associated with LD	Other conditions rarely associated with LD	Degenerative conditions associated with LD	LD but no condition specified
Septicaemia			✗					✗		
Cancers										
Cancer of nerves				✗✗✗						
Hypothyroidism excluding Iodine deficiency	✗✗									
Mental and behavioural disorders										
Unspecified dementia	✗✗									
Alzheimer's disease	✗✗✗									
Schizophrenia										✗✗
Diseases of the nervous system										
Parkinson's disease										✗
Epilepsy	✗✗	✗	✗		✗✗	✗	✗			✗✗
Paraplegia and tetraplegia		✗✗								
Hydrocephalus		✗								
Other disorders of brain			✗							
Heart diseases										
'Other' pulmonary heart diseases (I27)	✗									
Cardiac arrest						✗				
Heart failure						✗				
Respiratory diseases										
Pneumonia, organism unspecified	✗	✗	✗	✗	✗	✗	✗		✗	✗
Unspecified acute lower respiratory infection	✗	✗								
Asthma										✗
Pneumonitis due to solids and liquids	✗✗	✗✗	✗			✗	✗		✗	✗
Postprocedural respiratory disorders not elsewhere classified		✗								
Respiratory failure not elsewhere classified		✗	✗			✗	✗		✗	
'Other' respiratory disorders (J98)	✗	✗	✗			✗	✗		✗	✗

Table 4 (cont). Conditions more commonly associated with deaths for people with learning disabilities.

Condition	Down's syndrome	Cerebral Palsy	Hydrocephalus / Spina-bifida	Neurofibromatosis	Microcephaly	Other conditions usually associated with LD	Other conditions sometimes associated with LD	Other conditions rarely associated with LD	Degenerative conditions associated with LD	LD but no condition specified
Diseases of the digestive system										
Gastro-oesophageal reflux disease		✖✖								
Paralytic ileus and intestinal obstruction without hernia		✖								
Decubitus ulcer (pressure sores)			✖✖✖							
Scoliosis (curvature of the spine)		✖✖	✖✖✖							✖✖
Kidney diseases										
Chronic renal failure			✖			✖				
Unspecified renal failure			✖							
Urinary Tract Infection		✖								
Other disorders of urinary system	✖		✖✖							✖
Congenital disorders (there before birth)										
Malformations of septa of the heart	✖✖✖					✖✖				
Other heart malformations	✖✖					✖				
Signs and symptoms										
Involving the circulatory & respiratory systems		✖								
Dysphagia (difficulty swallowing)	✖✖									
Convulsions (fits)		✖								
Lack of normal development		✖			✖✖					✖✖✖
Accidents etc										
Foreign body in respiratory tract	✖	✖					✖			✖
Inhalation of stomach contents		✖								
Complications of treatment procedures			✖							
Late complications of surgery etc			✖					✖		

Table 5. Conditions less commonly associated with deaths for people with learning disabilities.

Condition	Down's syndrome	Cerebral Palsy	Hydrocephalus / Spina-bifida	Neurofibromatosis	Microcephaly	Other conditions usually associated with LD	Other conditions sometimes associated with LD	Other conditions rarely associated with LD	Degenerative conditions associated with LD	LD but no condition specified
Types of cancer										
Oesophagus	✓									✓
Stomach	✓	✓								✓
Colon	✓	✓	✓	✓				✓		✓
Rectum	✓	✓								
Liver and intrahepatic bile ducts	✓	✓								✓
Pancreas	✓	✓								✓
Other and ill-defined digestive organs	✓	✓								
Bronchus and lung	✓	✓	✓			✓	✓	✓	✓	✓
Breast	✓	✓	✓	✓		✓	✓	✓		✓
Ovary	✓	✓	✓							✓
Prostate	✓	✓								✓
Kidney, except renal pelvis	✓	✓								✓
Bladder	✓									
Brain	✓	✓	✓		✓	✓	✓		✓	✓
Secondary cancers in respiratory and digestive organs	✓	✓	✓							✓
Secondary cancers in other sites	✓	✓	✓							✓
Cancer, site not specified	✓	✓	✓			✓	✓	✓	✓	✓
Non-Hodgkin's lymphomas	✓	✓	✓							
Multiple myeloma and malignant plasma cell neoplasms	✓	✓								✓
Myeloid leukaemia	✓	✓	✓			✓			✓	
Diabetes			✓							
Mental and behavioural disorders										
Alcohol-related mental disorders	✓	✓	✓			✓	✓		✓	✓
Alzheimer's disease		✓								
Unspecified dementia		✓				✓				

Table 5 (cont). Conditions less commonly associated with deaths for people with learning disabilities.

Condition	Down's syndrome	Cerebral Palsy	Hydrocephalus / Spina-bifida	Neurofibromatosis	Microcephaly	Other conditions usually associated with LD	Other conditions sometimes associated with LD	Other conditions rarely associated with LD	Degenerative conditions associated with LD	LD but no condition specified
Blood pressure										
Essential (primary) hypertension	✓									
Hypertensive heart disease	✓	✓								✓
Heart diseases										
Acute myocardial infarction	✓	✓	✓	✓		✓			✓	✓
Chronic ischaemic heart disease	✓	✓	✓	✓						✓
Pulmonary embolism		✓								✓
Other diseases of pericardium	✓	✓								✓
Nonrheumatic aortic valve disorders										✓
Cardiomyopathy	✓	✓								✓
Cardiac arrest										
Atrial fibrillation and flutter		✓								✓
Heart failure		✓								
Complications and ill-defined descriptions of heart disease		✓								
Stroke										
Subarachnoid haemorrhage	✓	✓				✓				✓
Intracerebral haemorrhage	✓	✓								✓
Blood vessel diseases										
Atherosclerosis	✓	✓								✓
Aortic aneurysm and dissection	✓	✓								✓
Other peripheral vascular diseases	✓									✓
Phlebitis and thrombophlebitis		✓								✓

Table 5 (cont). Conditions less commonly associated with deaths for people with learning disabilities.

Condition	Down's syndrome	Cerebral Palsy	Hydrocephalus / Spina-bifida	Neurofibromatosis	Microcephaly	Other conditions usually associated with LD	Other conditions sometimes associated with LD	Other conditions rarely associated with LD	Degenerative conditions associated with LD	LD but no condition specified
Lung and chest diseases										
Emphysema	✓									
Other chronic obstructive pulmonary disease	✓	✓						✓		✓
Asthma									✓	
Other interstitial pulmonary diseases	✓	✓								
Digsetive system diseases										
Duodenal ulcer	✓									
Diverticular disease of intestine	✓									
Other diseases of intestine	✓									✓
Peritonitis	✓									
Alcoholic liver disease	✓	✓	✓	✓		✓	✓	✓	✓	✓
Fibrosis and cirrhosis of liver	✓	✓	✓					✓		✓
Other types of liver failure	✓	✓	✓							✓
Other diseases of liver	✓	✓								✓
Rheumatoid arthritis	✓									
Accidents and injuries										
Asphyxiation	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Fall unspecified		✓								
Late complications of surgery etc									✓	

Particular causes of death

Some of the causes of death mentioned are obviously related. The conditions 'foreign body in respiratory tract' and 'pneumonitis (lung inflammation) due to solids and liquids' are connected because the first causes the second. In people who have learning disabilities, both are usually related to food or drink 'going down the wrong way'. Similarly 'epilepsy' and the sign of 'convulsions' are probably related. We looked at these two groups of causes in more detail because they were common, affected most groups with learning disabilities or conditions causing this, and because there are things that can be done to prevent deaths from them.

Solids and liquids in the windpipe and lungs

Lung inflammation caused by solids or liquids, and foreign bodies in the windpipe, were involved in 1,048 deaths (14% of those identifiable) of people with learning disabilities or possibly associated conditions. In other people they were involved in just over 2%. Adjusting for ages at death, people dying with this were 9 times more likely than others to have a learning disability-related condition (95% confidence interval 8.5 to 9.6 times). Of the groups we studied, only those with neurofibromatosis, microcephaly and conditions rarely associated with learning disabilities (all small numbers) did not show this association. It was a particular problem for those with cerebral palsy, where 22% of identified deaths involved these conditions.

Dysphagia (difficulty swallowing) was mentioned on a small proportion (3%) of death certificates for people dying of the consequences of solids or liquids in their lungs or windpipe. However, where difficulty swallowing was mentioned, on the certificate, the cause of death in this group was solids or liquids in the lungs or windpipe in 60% of cases.

We looked at whether this appeared to change over time or vary between strategic health authority areas. There was no apparent trend over time. The geographic pattern is shown in map 1. There was some suggestion the problem was greater in East Anglia and the West Midlands and less in South Central and the South West Strategic health authorities, though we could not rule out the possibility that the differences seen were simply random chance.

Epilepsy and convulsions

Epilepsy or unspecified convulsions were involved in 948 deaths (13% of those identifiable) of people with learning disabilities or possibly associated conditions. In other people they were involved in 0.4%. Adjusting for ages at death, people dying with this were 9.7 times more likely than others to have a learning disability-related condition (95% confidence interval 9.1 to 10.4 times). This affected all groups except those with neurofibromatosis, conditions only rarely associated with learning disabilities and degenerative conditions associated with learning disabilities. While the proportions of deaths were less different in some years than others, there was no consistent rising or falling trend over time. Map 2 shows that the problem appeared to be greater in East Anglia and the West Midlands and less in London and the South East Coast strategic health authorities.

For both of these groups of causes we tested to see whether they could be affected by the possibility that doctors had not recorded learning disabilities specifically where deaths were due to causes that are not unusual in other people. Both Sheila Hollins and Freya Tyrer reported that only about 4 out of every 10 people who died from the learning disability registers they studied had their learning disability or its cause reported on their death certificate (see boxes above).[1 2] So we re-did the sums, assuming that we had only been able to identify 4 out of every 10 of the death certificates which actually related to people with learning disabilities, and that all the others did not include these causes of death. This reduced the difference, but in both cases, individuals dying of these causes were over three times more likely than others to have one of the conditions associated with learning disabilities.

Pneumonia

Pneumonia (not specified further) or lower respiratory tract infection, was mentioned on 2,626 (35%) death certificates of people with learning disabilities or possibly associated conditions. Adjusting for ages at death, people dying with these illnesses were 5 times more likely than others to have a learning disability-related condition (95% confidence interval 4.8 to 5.2 times).

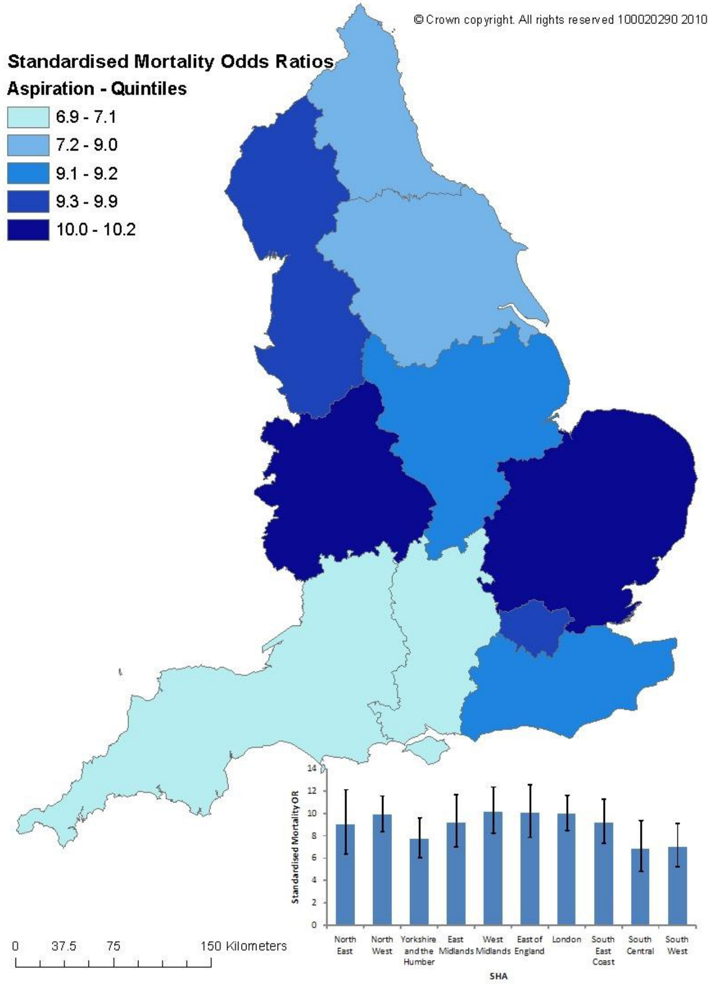
Sheila Hollins (see box above) pointed out the higher frequency of deaths with pneumonia for people of similar ages[2]. We found that these deaths fell almost evenly into two groups.

A bit more than a third (38%) had no other cause of death mentioned except the learning disability related one. It seemed they had got pneumonia and died. This was less common for people with Down's syndrome (33%), microcephaly (25%) and the other conditions rarely associated with learning disability, and more common for people with cerebral palsy (46%) and the degenerative conditions (67%), suggesting that aspects of physical nursing and medical complications of people's main conditions are involved.

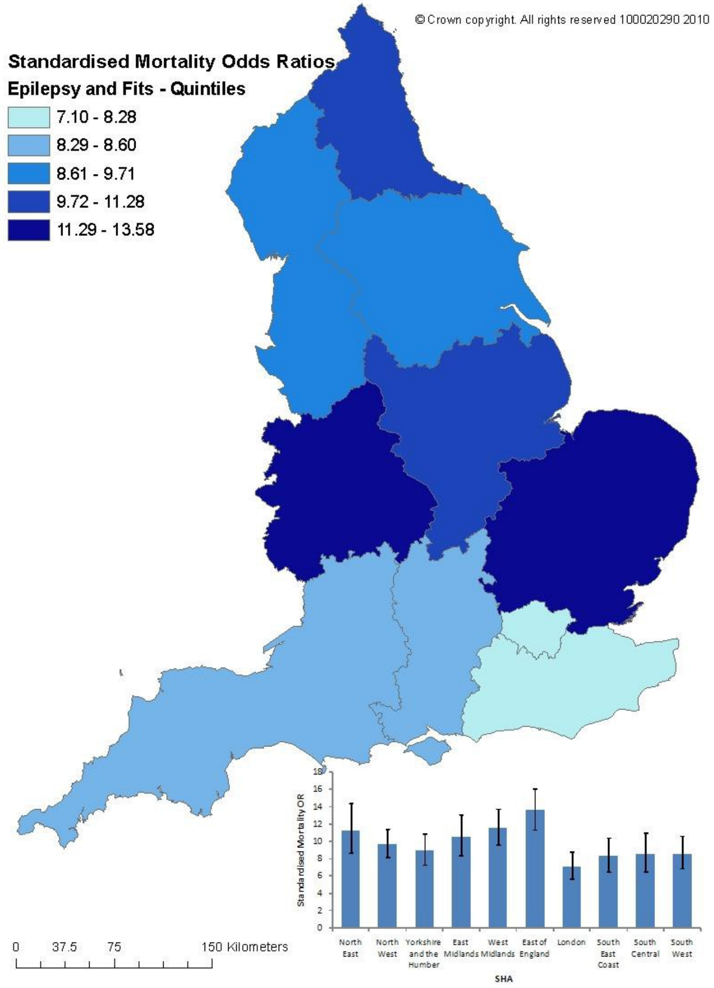
The other group had a wide range of other medical problems as well. We expected this as bronchopneumonia is a condition often developing in people who are terminally ill with other diseases such as cancer. The other conditions were very varied with no obvious major cluster.

Maps 1 and 2 show the variation around the country of how much more likely a person dying of these conditions is to have learning disabilities.

Map 1. Solids or liquids in the windpipe or lungs



Map 2. Epilepsy, fits or convulsions



Conclusions

Our aim was to see what we could learn from death certificates which could give pointers to reducing avoidable deaths.

We found that:

- Information from death certificates is easy to get, but the number of people reported as having learning disabilities (just over 1,000 per year) is below half what we would have expected.
- Ages at death
    - People with all types of indicator of learning disabilities die younger than other people.
    - People with learning disabilities reported but no physical condition causing this lived longest of the groups we studied, but the age by which half had died was still 15 years younger than for people with no learning disabilities.
    - People with Down's syndrome commonly die in their fifties and sixties, and people with hydrocephalus / spina bifida in their thirties and forties.
- Causes of death
    - When we looked at what people died of, many well know associations (like Down's syndrome with thyroid or hole-in-the-heart problems were clear.
    - Two causes stood out as particularly important because they are to some extent preventable, and were connected to large numbers of deaths across most groups of people with learning disabilities. They were:
        - Lung problems caused by solids or liquids going down the wrong way (14% of deaths where a condition associated with learning disabilities was reported), and
        - Epilepsy or convulsions (13% of deaths where a condition associated with learning disabilities was reported).
    - Just over 5% of people with hydrocephalus / spina-bifida died with pressure sores; in three quarters of cases this had led to an infection of the blood.

We plan to have a page on the Improving Health and Lives showing how many people with learning disabilities, or related conditions, die each year from lung problems caused by solids or liquids going down the wrong way, and from epilepsy or convulsions.

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Appendix table 1. Full listing of conditions associated with learning disabilities screened with numbers of deaths.

For each condition, the rate per 100,000 deaths and and 95% confidence interval is given. .

1. Conditions usually associated with learning disabilities

ICD10 code	TextVersion	Deaths (per 100k deaths)
D821	Di George's syndrome	22 (0.93 - 0.58 to 1.41)
E000	Congenital iodine-deficiency syndrome, neurological type	0
E001	Congenital iodine-deficiency syndrome, myxedematous type	0
E002	Congenital iodine-deficiency syndrome, mixed type	0
E009	Congenital iodine-deficiency syndrome, unspecified	1 (0.04 - 0.00 to 0.24)
E700	Classical phenylketonuria	1 (0.04 - 0.00 to 0.24)
E771	Defects in glycoprotein degradation	4 (0.17 - 0.05 to 0.43)
E778	Other disorders of glycoprotein metabolism	66 (2.79 - 2.16 to 3.55)
E791	Lesch-Nyhan syndrome	10 (0.42 - 0.20 to 0.78)
E798	Other disorders of purine and pyrimidine metabolism	0
F83	Mixed specific developmental disorders	17 (0.72 - 0.42 to 1.15)
F842	Rett's syndrome	53 (2.24 - 1.68 to 2.93)
F843	Other childhood disintegrative disorder	0
F844	Overactive disorder associated with mental retardation and stereotyped movements	0
F848	Other pervasive developmental disorders	0
F849	Pervasive developmental disorder, unspecified	0
Q00	Anencephaly and similar malformations	0
Q000	Anencephaly	1 (0.04 - 0.00 to 0.24)
Q001	Craniorachischisis	0
Q002	Iniencephaly	0
Q041	Arhinencephaly	0
Q042	Holoprosencephaly	18 (0.76 - 0.45 to 1.20)
Q043	Other reduction deformities of brain	91 (3.85 - 3.10 to 4.73)
Q048	Other specified congenital malformations of brain	24 (1.02 - 0.65 to 1.51)
Q851	Tuberous sclerosis	64 (2.71 - 2.09 to 3.46)
Q878	Other specified congenital malformation syndromes, not elsewhere classified	93 (3.94 - 3.18 to 4.82)
Q90	'Down's syndrome '	0
Q900	Trisomy 21, nonmosaicism (meiotic nondisjunction)	0
Q902	Trisomy 21, translocation	0
Q909	Down's syndrome, unspecified	2,163 (91.57 - 87.75 to 95.51)

Appendix table 1 (cont). Full listing of conditions associated with learning disabilities screened, numbers of deaths related to each cause, rate and 95% C.I. per 100,000 deaths.

1. Conditions usually associated with learning disabilities (cont)

ICD10 code	TextVersion	Deaths (per 100k deaths)
Q91	Edwards' syndrome and Patau's syndrome	0
Q910	Trisomy 18, nonmosaicism (meiotic nondisjunction)	0
Q911	Trisomy 18, mosaicism (mitotic nondisjunction)	0
Q912	Trisomy 18, translocation	0
Q913	Trisomy 18, unspecified	95 (4.02 - 3.25 to 4.92)
Q914	Trisomy 13, nonmosaicism (meiotic nondisjunction)	0
Q915	Trisomy 13, mosaicism (mitotic nondisjunction)	0
Q916	Trisomy 13, translocation	0
Q917	Trisomy 13, unspecified	37 (1.57 - 1.10 to 2.16)
Q92	Other trisomies and partial trisomies of the autosomes, not elsewhere classified	0
Q920	Whole chromosome trisomy, nonmosaicism (meiotic nondisjunction)	0
Q921	Whole chromosome trisomy, mosaicism (mitotic nondisjunction)	1 (0.04 - 0.00 to 0.24)
Q922	Partial trisomy	0
Q923	Minor partial trisomy	0
Q927	Triploidy and polyploidy	0
Q933	Deletion of short arm of chromosome 4	19 (0.80 - 0.48 to 1.26)
Q934	Deletion of short arm of chromosome 5	12 (0.51 - 0.26 to 0.89)
Q992	Fragile X chromosome	13 (0.55 - 0.29 to 0.94)

Appendix table 1 (cont). Full listing of conditions associated with learning disabilities screened, numbers of deaths related to each cause, rate and 95% C.I. per 100,000 deaths.

2. Conditions sometimes associated with learning disabilities

ICD10 code	TextVersion	Deaths (per 100k deaths)
A811	Subacute sclerosing panencephalitis	7 (0.30 - 0.12 to 0.61)
A818	Other atypical virus infections of central nervous system	2 (0.08 - 0.01 to 0.31)
B900	Sequelae of central nervous system tuberculosis	3 (0.13 - 0.03 to 0.37)
E70	Disorders of aromatic amino-acid metabolism	0
E701	Other hyperphenylalaninemias	13 (0.55 - 0.29 to 0.94)
E709	Disorder of aromatic amino-acid metabolism, unspecified	0
E723	Disorders of lysine and hydroxylysine metabolism	8 (0.34 - 0.15 to 0.67)
E75	Disorders of sphingolipid metabolism and other lipid storage disorders	0
E753	Sphingolipidosis, unspecified	0
E779	Disorder of glycoprotein metabolism, unspecified	1 (0.04 - 0.00 to 0.24)
F840	Autistic disorder	39 (1.65 - 1.17 to 2.26)
F841	Atypical autism	1 (0.04 - 0.00 to 0.24)
G80	Cerebral palsy	3 (0.13 - 0.03 to 0.37)
G800	Spastic quadriplegic cerebral palsy	21 (0.89 - 0.55 to 1.36)
G801	Spastic diplegic cerebral palsy	11 (0.47 - 0.23 to 0.83)
G802	Spastic hemiplegic cerebral palsy	15 (0.64 - 0.36 to 1.05)
G803	Athetoid cerebral palsy	10 (0.42 - 0.20 to 0.78)
G804	Ataxic cerebral palsy	0
G808	Other cerebral palsy	53 (2.24 - 1.68 to 2.93)
G809	Cerebral palsy, unspecified	1,756 (74.34 - 70.90 to 77.90)
P10	Intracranial laceration and haemorrhage due to birth injury	0
P100	Subdural hemorrhage due to birth injury	0
P101	Cerebral hemorrhage due to birth injury	0
P102	Intraventricular hemorrhage due to birth injury	0
P103	Subarachnoid hemorrhage due to birth injury	0
P104	Tentorial tear due to birth injury	0
P108	Other intracranial lacerations and hemorrhages due to birth injury	0
P109	Unspecified intracranial laceration and hemorrhage due to birth injury	0
P110	Cerebral edema due to birth injury	0
P111	Other specified brain damage due to birth injury	1 (0.04 - 0.00 to 0.24)
P112	Unspecified brain damage due to birth injury	8 (0.34 - 0.15 to 0.67)
P119	Birth injury to central nervous system, unspecified	1 (0.04 - 0.00 to 0.24)

Appendix table 1 (cont). Full listing of conditions associated with learning disabilities screened, numbers of deaths related to each cause, rate and 95% C.I. per 100,000 deaths.

2. Conditions sometimes associated with learning disabilities (cont)

ICD10 code	TextVersion	Deaths (per 100k deaths)
Q01	Encephalocele	0
Q010	Frontal encephalocele	0
Q011	Nasofrontal encephalocele	0
Q012	Occipital encephalocele	1 (0.04 - 0.00 to 0.24)
Q018	Encephalocele of other sites	0
Q019	Encephalocele, unspecified	6 (0.25 - 0.09 to 0.55)
Q02	Microcephaly	154 (6.52 - 5.53 to 7.63)
Q030	Malformations of aqueduct of Sylvius	9 (0.38 - 0.17 to 0.72)
Q031	Atresia of foramina of Magendie and Luschka	22 (0.93 - 0.58 to 1.41)
Q039	Congenital hydrocephalus, unspecified	169 (7.15 - 6.12 to 8.32)
Q04	Other congenital malformations of brain	1 (0.04 - 0.00 to 0.24)
Q045	Megalencephaly	1 (0.04 - 0.00 to 0.24)
Q046	Congenital cerebral cysts	40 (1.69 - 1.21 to 2.31)
Q049	Congenital malformation of brain, unspecified	91 (3.85 - 3.10 to 4.73)
Q05	Spina bifida	1 (0.04 - 0.00 to 0.24)
Q050	Cervical spina bifida with hydrocephalus	0
Q051	Thoracic spina bifida with hydrocephalus	0
Q052	Lumbar spina bifida with hydrocephalus	0
Q053	Sacral spina bifida with hydrocephalus	0
Q054	Unspecified spina bifida with hydrocephalus	38 (1.61 - 1.14 to 2.21)
Q059	Spina bifida, unspecified	344 (14.56 - 13.06 to 16.19)
Q85	Phakomatoses, not elsewhere classified	2 (0.08 - 0.01 to 0.31)
Q850	Neurofibromatosis (nonmalignant)	234 (9.91 - 8.68 to 11.26)
Q859	Phakomatosis, unspecified	6 (0.25 - 0.09 to 0.55)
Q860	Fetal alcohol syndrome (dysmorphic)	3 (0.13 - 0.03 to 0.37)
Q871	Congenital malformation syndromes predominantly associated with short stature	140 (5.93 - 4.99 to 6.99)

Appendix table 1 (cont). Full listing of conditions associated with learning disabilities screened, numbers of deaths related to each cause, rate and 95% C.I. per 100,000 deaths.

2. Conditions sometimes associated with learning disabilities (cont)

ICD10 code	TextVersion	Deaths (per 100k deaths)
Q901	Trisomy 21, mosaicism (mitotic nondisjunction)	0
Q924	Duplications seen only at prometaphase	0
Q925	Duplications with other complex rearrangements	4 (0.17 - 0.05 to 0.43)
Q926	Extra marker chromosomes	0
Q928	Other specified trisomies and partial trisomies of autosomes	24 (1.02 - 0.65 to 1.51)
Q929	Trisomy and partial trisomy of autosomes, unspecified	7 (0.30 - 0.12 to 0.61)
Q93	Monosomies and deletions from the autosomes, not elsewhere classified	0
Q932	Chromosome replaced with ring, dicentric or isochromosome	1 (0.04 - 0.00 to 0.24)
Q935	Other deletions of part of a chromosome	31 (1.31 - 0.89 to 1.86)
Q936	Deletions seen only at prometaphase	0
Q937	Deletions with other complex rearrangements	1 (0.04 - 0.00 to 0.24)
Q938	Other deletions from the autosomes	12 (0.51 - 0.26 to 0.89)
Q939	Deletion from autosomes, unspecified	1 (0.04 - 0.00 to 0.24)
Q950	Balanced translocation and insertion in normal individual	0
Q951	Chromosome inversion in normal individual	1 (0.04 - 0.00 to 0.24)
Q952	Balanced autosomal rearrangement in abnormal individual	0
Q953	Balanced sex/autosomal rearrangement in abnormal individual	0
Q954	Individuals with marker heterochromatin	0
Q955	Individual with autosomal fragile site	0

Appendix table 1 (cont). Full listing of conditions associated with learning disabilities screened, numbers of deaths related to each cause, rate and 95% C.I. per 100,000 deaths.

3. Conditions rarely associated with learning disabilities

ICD10 code	TextVersion	Deaths (per 100k deaths)
E702	Disorders of tyrosine metabolism	5 (0.21 - 0.07 to 0.49)
E720	Disorders of amino-acid transport	20 (0.85 - 0.52 to 1.31)
E721	Disorders of sulfur-bearing amino-acid metabolism	6 (0.25 - 0.09 to 0.55)
E722	Disorders of urea cycle metabolism	6 (0.25 - 0.09 to 0.55)
E724	Disorders of ornithine metabolism	4 (0.17 - 0.05 to 0.43)
E741	Disorders of fructose metabolism	0
E742	Disorders of galactose metabolism	3 (0.13 - 0.03 to 0.37)
E744	Disorders of pyruvate metabolism and gluconeogenesis	11 (0.47 - 0.23 to 0.83)
E803	Defects of catalase and peroxidase	0
E804	Gilbert's syndrome	8 (0.34 - 0.15 to 0.67)
E806	Other disorders of bilirubin metabolism	4 (0.17 - 0.05 to 0.43)
E851	Neuropathic heredofamilial amyloidosis	1 (0.04 - 0.00 to 0.24)
Q055	Cervical spina bifida without hydrocephalus	0
Q056	Thoracic spina bifida without hydrocephalus	1 (0.04 - 0.00 to 0.24)
Q057	Lumbar spina bifida without hydrocephalus	0
Q058	Sacral spina bifida without hydrocephalus	0
Q070	Arnold-Chiari syndrome	40 (1.69 - 1.21 to 2.31)
Q796	Ehlers-Danlos syndrome	32 (1.35 - 0.93 to 1.91)
Q858	Other phakomatoses, not elsewhere classified	61 (2.58 - 1.98 to 3.32)
Q86	Congenital malformation syndromes due to known exogenous causes, not elsewhere classified	0
Q861	Fetal hydantoin syndrome	0
Q862	Dysmorphism due to warfarin	0
Q930	Whole chromosome monosomy, nonmosaicism (meiotic nondisjunction)	0
Q931	Whole chromosome monosomy, mosaicism (mitotic nondisjunction)	0

Appendix table 1 (cont). Full listing of conditions associated with learning disabilities screened, numbers of deaths related to each cause, rate and 95% C.I. per 100,000 deaths.

3. Conditions rarely associated with learning disabilities (cont)

ICD10 code	TextVersion	Deaths (per 100k deaths)
Q96	'Turner's syndrome '	0
Q960	Karyotype 45, X	0
Q961	Karyotype 46, X iso (Xq)	0
Q962	Karyotype 46, X with abnormal sex chromosome, except iso (Xq)	0
Q963	Mosaicism, 45, X/46, XX or XY	1 (0.04 - 0.00 to 0.24)
Q964	Mosaicism, 45, X/other cell line(s) with abnormal sex chromosome	0
Q968	Other variants of Turner's syndrome	0
Q969	Turner's syndrome, unspecified	44 (1.86 - 1.35 to 2.50)
Q97	Other sex chromosome abnormalities, female phenotype, not elsewhere classified	0
Q971	Female with more than three X chromosomes	1 (0.04 - 0.00 to 0.24)
Q978	Other specified sex chromosome abnormalities, female phenotype	1 (0.04 - 0.00 to 0.24)
Q980	Klinefelter syndrome karyotype 47, XXY	1 (0.04 - 0.00 to 0.24)
Q981	Klinefelter syndrome, male with more than two X chromosomes	0
Q982	Klinefelter's syndrome, male with 46,XX karyotype	0
Q983	Other male with 46, XX karyotype	0
Q984	Klinefelter syndrome, unspecified	14 (0.59 - 0.32 to 0.99)
Q985	Karyotype 47, XYY	0
Q986	Male with structurally abnormal sex chromosome	0
Q987	Male with sex chromosome mosaicism	0
Q989	Sex chromosome abnormality, male phenotype, unspecified	1 (0.04 - 0.00 to 0.24)

Appendix table 1 (cont). Full listing of conditions associated with learning disabilities screened, numbers of deaths related to each cause, rate and 95% C.I. per 100,000 deaths.

4. Degenerative conditions associated with learning disabilities

ICD10 code	TextVersion	Deaths (per 100k deaths)
E740	Glycogen storage disease	29 (1.23 - 0.82 to 1.76)
E750	GM2 gangliosidosis	22 (0.93 - 0.58 to 1.41)
E751	Other gangliosidosis	22 (0.93 - 0.58 to 1.41)
E752	Other sphingolipidosis	142 (6.01 - 5.06 to 7.09)
E754	Neuronal ceroid lipofuscinosis	60 (2.54 - 1.94 to 3.27)
E755	Other lipid storage disorders	4 (0.17 - 0.05 to 0.43)
E756	Lipid storage disorder, unspecified	2 (0.08 - 0.01 to 0.31)
E76	Disorders of glycosaminoglycan metabolism	0
E760	Mucopolysaccharidosis, type I	15 (0.64 - 0.36 to 1.05)
E761	Mucopolysaccharidosis, type II	21 (0.89 - 0.55 to 1.36)
E762	Other mucopolysaccharidoses	41 (1.74 - 1.25 to 2.35)
E763	Mucopolysaccharidosis, unspecified	8 (0.34 - 0.15 to 0.67)
E768	Other disorders of glucosaminoglycan metabolism	0
E769	Glucosaminoglycan metabolism disorder, unspecified	0
E770	Defects in post-translational modification of lysosomal enzymes	12 (0.51 - 0.26 to 0.89)

Appendix table 2. The five most common immediate causes of death, for each of the learning disability groups

1. Down's Syndrome

0 to 4	5 to 14	15 to 24	25 to 34	35 to 44	45 to 54	55 to 64	65 and over
Respiratory diseases (36 - 26.9%)	Respiratory diseases (10 - 37.0%)	Respiratory diseases (18 - 42.9%)	Circulatory diseases (25 - 36.2%)	Respiratory diseases (56 - 42.1%)	Respiratory diseases (280 - 62.4%)	Respiratory diseases (737 - 69.9%)	Respiratory diseases (180 - 70.9%)
Circulatory diseases (36 - 26.9%)	Circulatory diseases (8 - 29.6%)	Circulatory diseases (12 - 28.6%)	Respiratory diseases (20 - 29.0%)	Circulatory diseases (34 - 25.6%)	Circulatory diseases (60 - 13.4%)	Circulatory diseases (102 - 9.7%)	Circulatory diseases (23 - 9.1%)
Infectious and parasitic diseases (18 - 13.4%)			Congenital and chromosomal conditions (7 - 10.1%)	Congenital and chromosomal conditions (10 - 7.5%)	Infectious and parasitic diseases (19 - 4.2%)	Infectious and parasitic diseases (53 - 5.0%)	Other signs and symptoms (11 - 4.3%)
Congenital and chromosomal conditions (13 - 9.7%)				Digestive system diseases (6 - 4.5%)	Nervous system diseases (19 - 4.2%)	Nervous system diseases (50 - 4.7%)	Infectious and parasitic diseases (9 - 3.5%)
Other signs and symptoms (12 - 9.0%)				Infectious and parasitic diseases (6 - 4.5%)	Mental and behavioural disorders (15 - 3.3%)	Mental and behavioural disorders (33 - 3.1%)	Mental and behavioural disorders (8 - 3.1%)

Figures after each cause show the number of deaths and the percentage of deaths in each age group. Only causes where five or more deaths were reported are shown. Comparable figures for people without learning disabilities are shown at the end of this set of tables.

Appendix table 2 (cont). The five most common immediate causes of death, for each of the learning disability groups, by age group.

2. Cerebral Palsy

0 to 4	**5 to 14**	**15 to 24**	**25 to 34**	**35 to 44**	**45 to 54**	**55 to 64**	**65 and over**
Respiratory diseases (104 - 53.1%)	Respiratory diseases (150 - 57.0%)	Respiratory diseases (212 - 68.6%)	Respiratory diseases (120 - 72.7%)	Respiratory diseases (134 - 62.9%)	Respiratory diseases (126 - 64.6%)	Respiratory diseases (126 - 60.3%)	Respiratory diseases (207 - 65.1%)
Nervous system diseases (27 - 13.8%)	Nervous system diseases (37 - 14.1%)	Nervous system diseases (29 - 9.4%)	Circulatory diseases (10 - 6.1%)	Infectious and parasitic diseases (15 - 7.0%)	Infectious and parasitic diseases (19 - 9.7%)	Infectious and parasitic diseases (16 - 7.7%)	Circulatory diseases (26 - 8.2%)
Other signs and symptoms (16 - 8.2%)	Other signs and symptoms (24 - 9.1%)	Circulatory diseases (19 - 6.1%)	Nervous system diseases (9 - 5.5%)	Circulatory diseases (14 - 6.6%)	Nervous system diseases (13 - 6.7%)	Cancers and other growths (13 - 6.2%)	Infectious and parasitic diseases (25 - 7.9%)
Infectious and parasitic diseases (15 - 7.7%)	Circulatory diseases (15 - 5.7%)	Other signs and symptoms (14 - 4.5%)	Other signs and symptoms (6 - 3.6%)	Digestive system diseases (11 - 5.2%)	Circulatory diseases (13 - 6.7%)	Circulatory diseases (12 - 5.7%)	Other signs and symptoms (15 - 4.7%)
Circulatory diseases (12 - 6.1%)	Injury and poisoning (10 - 3.8%)	Infectious and parasitic diseases (13 - 4.2%)	Infectious and parasitic diseases (6 - 3.6%)	Nervous system diseases (9 - 4.2%)	Cancers and other growths (8 - 4.1%)	Nervous system diseases (11 - 5.3%)	Digestive system diseases (12 - 3.8%)

Figures after each cause show the number of deaths and the percentage of deaths in each age group. Only causes where five or more deaths were reported are shown. Comparable figures for people without learning disabilities are shown at the end of this set of tables.

Appendix table 2 (cont). The five most common immediate causes of death, for each of the learning disability groups, by age group.

3. Hydrocephalus / Spina-bifida

0 to 4	**5 to 14**	**15 to 24**	**25 to 34**	**35 to 44**	**45 to 54**	**55 to 64**	**65 and over**
Respiratory diseases (15 - 25.9%)	Circulatory diseases (5 - 23.8%)	Respiratory diseases (17 - 41.5%)	Respiratory diseases (15 - 20.5%)	Respiratory diseases (57 - 34.8%)	Respiratory diseases (23 - 38.3%)	Respiratory diseases (14 - 33.3%)	Respiratory diseases (16 - 25.0%)
Congenital and chromosomal conditions (12 - 20.7%)	Respiratory diseases (5 - 23.8%)	Nervous system diseases (5 - 12.2%)	Circulatory diseases (11 - 15.1%)	Infectious and parasitic diseases (27 - 16.5%)	Circulatory diseases (12 - 20.0%)	Circulatory diseases (7 - 16.7%)	Infectious and parasitic diseases (15 - 23.4%)
Illnesses in newborn infants (11 - 19.0%)			Nervous system diseases (11 - 15.1%)	Circulatory diseases (21 - 12.8%)	Infectious and parasitic diseases (5 - 8.3%)	Infectious and parasitic diseases (5 - 11.9%)	Circulatory diseases (10 - 15.6%)
Nervous system diseases (8 - 13.8%)			Infectious and parasitic diseases (10 - 13.7%)	Genito-urinary diseases (12 - 7.3%)			Cancers and other growths (7 - 10.9%)
			Genito-urinary diseases (8 - 11.0%)	Nervous system diseases (11 - 6.7%)			Genito-urinary diseases (6 - 9.4%)
				Injury and poisoning (11 - 6.7%)			

Figures after each cause show the number of deaths and the percentage of deaths in each age group. Only causes where five or more deaths were reported are shown. Comparable figures for people without learning disabilities are shown at the end of this set of tables. In the 35 to 44 age group six causes are shown as there were two tied fifth-placed causes.

Appendix table 2 (cont). The five most common immediate causes of death, for each of the learning disability groups, by age group.

4. Neurofibromatosis

0 to 4	**5 to 14**	**15 to 24**	**25 to 34**	**35 to 44**	**45 to 54**	**55 to 64**	**65 and over**
		Cancers and other growths (13 - 65.0%)	Cancers and other growths (16 - 53.3%)	Cancers and other growths (13 - 33.3%)	Respiratory diseases (9 - 32.1%)	Respiratory diseases (13 - 48.1%)	Respiratory diseases (30 - 37.5%)
			Respiratory diseases (5 - 16.7%)	Respiratory diseases (11 - 28.2%)	Cancers and other growths (8 - 28.6%)		Circulatory diseases (15 - 18.8%)
					Circulatory diseases (6 - 21.4%)		Cancers and other growths (14 - 17.5%)
							Infectious and parasitic diseases (7 - 8.8%)
							Other signs and symptoms (5 - 6.3%)

Figures after each cause show the number of deaths and the percentage of deaths in each age group. Only causes where five or more deaths were reported are shown. Comparable figures for people without learning disabilities are shown at the end of this set of tables.

Appendix table 2 (cont). The five most common immediate causes of death, for each of the learning disability groups, by age group.

5. Microcephaly

0 to 4	**5 to 14**	**15 to 24**	**25 to 34**	**35 to 44**	**45 to 54**	**55 to 64**	**65 and over**
Respiratory diseases (35 - 51.5%)	Respiratory diseases (16 - 57.1%)	Respiratory diseases (8 - 57.1%)	Respiratory diseases (8 - 53.3%)		Respiratory diseases (5 - 55.6%)		
Other signs and symptoms (9 - 13.2%)							
Congenital and chromosomal conditions (8 - 11.8%)							
Circulatory diseases (5 - 7.4%)							

Figures after each cause show the number of deaths and the percentage of deaths in each age group. Only causes where five or more deaths were reported are shown. Comparable figures for people without learning disabilities are shown at the end of this set of tables.

Appendix table 2 (cont). The five most common immediate causes of death, for each of the learning disability groups, by age group.

6. Other conditions usually associated with learning disabilities

0 to 4	5 to 14	15 to 24	25 to 34	35 to 44	45 to 54	55 to 64	65 and over
Congenital and chromosomal conditions (125 - 41.1%)	Respiratory diseases (25 - 54.3%)	Respiratory diseases (36 - 63.2%)	Respiratory diseases (14 - 38.9%)	Respiratory diseases (17 - 38.6%)	Respiratory diseases (7 - 25.9%)	Respiratory diseases (10 - 45.5%)	Respiratory diseases (30 - 36.6%)
Respiratory diseases (93 - 30.6%)	Circulatory diseases (5 - 10.9%)	Nervous system diseases (7 - 12.3%)	Circulatory diseases (6 - 16.7%)	Circulatory diseases (8 - 18.2%)	Circulatory diseases (6 - 22.2%)	Circulatory diseases (5 - 22.7%)	Circulatory diseases (22 - 26.8%)
Circulatory diseases (20 - 6.6%)							Infectious and parasitic diseases (6 - 7.3%)
Other signs and symptoms (20 - 6.6%)							Hormonal, nutritional and metabolic diseases (5 - 6.1%)
Infectious and parasitic diseases (12 - 3.9%)							Cancers and other growths (5 - 6.1%)
							Genito-urinary diseases (5 - 6.1%)

Figures after each cause show the number of deaths and the percentage of deaths in each age group. Only causes where five or more deaths were reported are shown. Comparable figures for people without learning disabilities are shown at the end of this set of tables. In the 65 and over age group six causes are shown as there were three tied fourth-placed causes.

Appendix table 2 (cont). The five most common immediate causes of death, for each of the learning disability groups, by age group.

7. Other conditions sometimes associated with learning disabilities

0 to 4	**5 to 14**	**15 to 24**	**25 to 34**	**35 to 44**	**45 to 54**	**55 to 64**	**65 and over**
Respiratory diseases (31 - 26.1%)	Respiratory diseases (21 - 44.7%)	Respiratory diseases (15 - 29.4%)	Respiratory diseases (24 - 39.3%)	Infectious and parasitic diseases (3 - 4.9%)	Circulatory diseases (12 - 36.4%)	Respiratory diseases (8 - 32.0%)	Respiratory diseases (14 - 45.2%)
Congenital and chromosomal conditions (22 - 18.5%)	Circulatory diseases (7 - 14.9%)	Nervous system diseases (9 - 17.6%)	Circulatory diseases (13 - 21.3%)	Congenital and chromosomal conditions (3 - 4.9%)	Respiratory diseases (12 - 36.4%)	Circulatory diseases (6 - 24.0%)	Circulatory diseases (10 - 32.3%)
Circulatory diseases (17 - 14.3%)	Congenital and chromosomal conditions (6 - 12.8%)	Circulatory diseases (9 - 17.6%)	Nervous system diseases (8 - 13.1%)	Respiratory diseases (17 - 32.1%)			
Other signs and symptoms (16 - 13.4%)				Circulatory diseases (12 - 22.6%)			
Illnesses in newborn infants (10 - 8.4%)				Nervous system diseases (7 - 13.2%)			

Figures after each cause show the number of deaths and the percentage of deaths in each age group. Only causes where five or more deaths were reported are shown. Comparable figures for people without learning disabilities are shown at the end of this set of tables.

Appendix table 2 (cont). The five most common immediate causes of death, for each of the learning disability groups, by age group.

8. Other conditions rarely associated with learning disabilities

0 to 4	5 to 14	15 to 24	25 to 34	35 to 44	45 to 54	55 to 64	65 and over
Hormonal, nutritional and metabolic diseases (5 - 27.8%)			Respiratory diseases (6 - 31.6%)	Circulatory diseases (15 - 45.5%)	Circulatory diseases (16 - 32.7%)	Circulatory diseases (9 - 31.0%)	Respiratory diseases (24 - 33.8%)
			Circulatory diseases (5 - 26.3%)		Respiratory diseases (12 - 24.5%)	Cancers and other growths (6 - 20.7%)	Circulatory diseases (18 - 25.4%)
					Infectious and parasitic diseases (7 - 14.3%)	Genito-urinary diseases (5 - 17.2%)	Cancers and other growths (7 - 9.9%)
					Cancers and other growths (6 - 12.2%)	Respiratory diseases (5 - 17.2%)	

Figures after each cause show the number of deaths and the percentage of deaths in each age group. Only causes where five or more deaths were reported are shown. Comparable figures for people without learning disabilities are shown at the end of this set of tables.

Appendix table 2 (cont). The five most common immediate causes of death, for each of the learning disability groups, by age group.

9. Degenerative conditions associated with learning disabilities

0 to 4	**5 to 14**	**15 to 24**	**25 to 34**	**35 to 44**	**45 to 54**	**55 to 64**	**65 and over**
Respiratory diseases (45 - 45.0%)	Respiratory diseases (57 - 50.4%)	Respiratory diseases (32 - 53.3%)	Respiratory diseases (10 - 40.0%)	Respiratory diseases (8 - 33.3%)	Respiratory diseases (9 - 56.3%)	Respiratory diseases (10 - 52.6%)	Respiratory diseases (8 - 42.1%)
Hormonal, nutritional and metabolic diseases (27 - 27.0%)	Hormonal, nutritional and metabolic diseases (39 - 34.5%)	Hormonal, nutritional and metabolic diseases (16 - 26.7%)	Hormonal, nutritional and metabolic diseases (7 - 28.0%)	Circulatory diseases (8 - 33.3%)			
Other signs and symptoms (9 - 9.0%)	Circulatory diseases (8 - 7.1%)						
Circulatory diseases (9 - 9.0%)							

Figures after each cause show the number of deaths and the percentage of deaths in each age group. Only causes where five or more deaths were reported are shown. Comparable figures for people without learning disabilities are shown at the end of this set of tables.

Appendix table 2 (cont). The five most common immediate causes of death, for each of the learning disability groups, by age group.

10. Learning disability, but no condition specified

0 to 4	5 to 14	15 to 24	25 to 34	35 to 44	45 to 54	55 to 64	65 and over
		Respiratory diseases (14 - 51.9%)	Respiratory diseases (12 - 41.4%)	Respiratory diseases (33 - 44.0%)	Respiratory diseases (61 - 50.4%)	Respiratory diseases (90 - 52.6%)	Respiratory diseases (229 - 50.7%)
			Circulatory diseases (5 - 17.2%)	Nervous system diseases (9 - 12.0%)	Circulatory diseases (15 - 12.4%)	Circulatory diseases (16 - 9.4%)	Circulatory diseases (61 - 13.5%)
				Cancers and other growths (7 - 9.3%)	Injury and poisoning (12 - 9.9%)	Cancers and other growths (15 - 8.8%)	Other signs and symptoms (41 - 9.1%)
				Genito-urinary diseases (6 - 8.0%)	Cancers and other growths (11 - 9.1%)	Infectious and parasitic diseases (12 - 7.0%)	Infectious and parasitic diseases (36 - 8.0%)
				Infectious and parasitic diseases (5 - 6.7%)	Infectious and parasitic diseases (9 - 7.4%)		Cancers and other growths (27 - 6.0%)

Figures after each cause show the number of deaths and the percentage of deaths in each age group. Only causes where five or more deaths were reported are shown. Comparable figures for people without learning disabilities are shown at the end of this set of tables.

Appendix table 2 (cont). The five most common immediate causes of death by age group for people with no reported learning disability .

0 to 4	**5 to 14**	**15 to 24**	**25 to 34**	**35 to 44**	**45 to 54**	**55 to 64**	**65 and over**
Stillborn (10,696 - 63.4%)	Injury and poisoning (675 - 25.6%)	Injury and poisoning (6,504 - 56.0%)	Injury and poisoning (8,164 - 42.1%)	Cancers and other growths (10,471 - 23.3%)	Cancers and other growths (30,190 - 32.7%)	Cancers and other growths (81,138 - 39.2%)	Circulatory diseases (587,944 - 30.0%)
Other signs and symptoms (1,318 - 7.8%)	Cancers and other growths (615 - 23.3%)	Cancers and other growths (1,054 - 9.1%)	Circulatory diseases (2,630 - 13.6%)	Injury and poisoning (9,832 - 21.8%)	Circulatory diseases (24,028 - 26.0%)	Circulatory diseases (55,232 - 26.7%)	Respiratory diseases (551,582 - 28.1%)
Respiratory diseases (927 - 5.5%)	Respiratory diseases (409 - 15.5%)	Circulatory diseases (1,010 - 8.7%)	Cancers and other growths (2,629 - 13.6%)	Circulatory diseases (9,404 - 20.9%)	Respiratory diseases (11,201 - 12.1%)	Respiratory diseases (31,693 - 15.3%)	Cancers and other growths (391,754 - 20.0%)
Illnesses of newborn infants (721 - 4.3%)	Circulatory diseases (272 - 10.3%)	Respiratory diseases (973 - 8.4%)	Respiratory diseases (1,667 - 8.6%)	Respiratory diseases (4,428 - 9.8%)	Digestive system diseases (8,592 - 9.3%)	Digestive system diseases (12,354 - 6.0%)	Other signs and symptoms (149,834 - 7.6%)
Circulatory diseases (606 - 3.6%)	Nervous system diseases (228 - 8.6%)	Other signs and symptoms (631 - 5.4%)	Other signs and symptoms (1,187 - 6.1%)	Digestive system diseases (4,263 - 9.5%)	Injury and poisoning (8,004 - 8.7%)	Infectious and parasitic diseases (7,284 - 3.5%)	Infectious and parasitic diseases (89,708 - 4.6%)

Area of Audit	**Comments**	**Solutions / Actions**
General Practitioners are not routinely involved with annual health checks in Sunderland. Only 38% of the sample audited had a GP involved in the check.	The DES requires a lead GP to be involved and to deliver some of the elements of the check such as physical examination and medication review.	We need to agree with practices how GPs will be involved in annual health checks going forward.
Learning Disability Awareness training has not been available in the last two years, delivered by NTW staff yet 61% of checks audited suggested they had received training.	We need to understand fully what training has been received, by whom and if it was informative.	Training needs to be consistent. Maybe delivered at TITO or if that's too big in localities to ensure everyone is trained. E learning and bespoke practice training to be introduced.
The length of annual health checks is extremely variable from 6 minutes to 31-40 minutes. A thorough annual health check would take at least 30 to 40 minutes.	If a detailed useful check is to take place then the times suggested in the audit are too short.	There is always going to be a difference in health check consultation lengths as every patient varies in their disability. As long as the correct information is captured and the patient is cared for there shouldn't be a time put around this, however it is usually not possible to gather the required information in less than 30 minutes.
Only 10% of annual health checks that were audited in the sample involved an abdominal examination. 28.3 % involved heart and chest checks. 16% involved urinalysis.	We need to understand if the numbers are low due to the skill of the health professional providing the check or if it is not felt to be required.	Further evidence to be gathered beyond the initial audit to quantify the scale of this issue.

Area of Audit	**Comments**	**Solutions / Actions**
According to the audit 71.7% of patients had a flu vaccine which was positive however this is only a 10% sample as the actual figure across Sunderland who had their flu vaccine last year was 43%	We are supporting with the winter plan this year and at the end of October only 33% of people eligible have had flu vaccine. Can we use the annual health check to gain consent to share information regarding support available (NTW) for flu vaccines.	Communication to be rolled out to all practices to attempt to gain consent at next planned appointment or annual health check in regards to sharing information where health promotion team could be asked to support the patient.
35% of checks audited were using the paper based Cardiff tool whilst 55% were using a locally devised tool.	This understandably causes variance across Sunderland and what is provided.	Standardised NHS England Template needs to be implemented.
35% of new problems were identified at the annual health check.	This is a positive outcome.	
41% of patients had referrals made as a result of their annual health check	It would be good to understand fully what kind of referrals are been made.	Further analysis of this data is required.
According to the sample 41.7% had a health action plan.	There is a huge misunderstanding about health action plans and this figure would not be representative over a bigger sample .	Clear training is required so the concept of health action planning is understood.

Mental Capacity Act 2005

The 5 Principles

bild

Principle 1: Assume a person has capacity unless proved otherwise.

Principle 2: Do not treat people as incapable of making a decision unless all practicable steps have been tried to help them.

Principle 3: A person should not be treated as incapable of making a decision because their decision may seem unwise.

Principle 4: Always do things or take decisions for people without capacity in their best interests.

Principle 5: Before doing something to someone or making a decision on their behalf, consider whether the outcome could be achieved in a less restrictive way.

www.bild.org.uk

Flu Protocol 2016/2017

Appendix 6

Introduction

The Community Treatment Team for Learning Disabilities in Sunderland have agreed to work in partnership with Sunderland Clinical Commissioning Group to support the GP practices with difficult to reach complex patients who may not ordinarily have their flu vaccine. A separate action plan has been developed and implemented to support this across the city.

This protocol will simply outline the process and arrangements for obtaining the flu vaccine from the practice to administer to the patient and the documentation in relation to the administration of it.

1. The GP practice will contact IRS on 0303 123 1145 if they wish to make a referral for a patient to have their flu immunisation where it has not been possible to administer at the practice or patients home. A list of reasonable adjustments is in the Appendix of this document;
2. The GP practice will ask if the patient is already known to the learning disability team, if they are IRS will simply email the allocated professional who will make the necessary arrangement's to have the flu vaccine given by a trained nurse;
3. If the patient is not known to the community treatment team then IRS will open the referral and email Ashley Murphy who will coordinate the new referral and ensure it is allocated;
4. IRS will ask the GP practice a series of questions to check out that all reasonable adjustments have taken place first;
5. Once the learning disability nurse has been allocated to the patient, they will take responsibility for visiting the practice with the relevant documentation, also in the appendix of this document. This document will be completed to say they have collected the flu vaccine, with details of the batch number;
6. If the administration of the vaccine is successful the nurse will then electronically send the document back to the practice so the records can be updated to reflect the vaccine has been given. Equally if it has not been successful the practice will be informed and the vaccine returned or disposed of accordingly.

The Role of the Health Promotion Team:

1. The health promotion team are working with each practice across the city to help each practice to identify people with learning disabilities on their register who have not had the vaccine in the past;
2. Once this has been done the practice will seek consent from the patients and those who know them best to establish if they would like the health promotion team to become involved to help them either access the clinic or additional support to help them become less anxious for example via the community team;
3. It maybe that they can support them to visit the practice, explore their anxieties, help them to understand and if not they will ask the nurses within the community treatment team to administer the vaccine where possible.

Developed in discussion with:

- Chrissie Todd – West Locality Practice Manager, Practice Manager;
- Jackie Russell – Washington Locality Practice Manager, Practice Manager;
- Linda Reiling – Joint Commissioning Manager (Mental Health & Learning Disabilities) Sunderland CCG Dementia Lead;
- Amanda Hunter – Learning disability Community Nurse;
- Ashley Murphy – Primary & Secondary Care Health Facilitation Nurse.

Appendix 1

Example of Reasonable adjustments to try before making referral for the flu vaccinne to be given by NTW.

1. Is the issue environmental - could the practice nurse go out to the person's home to administer it?
2. Is there a person in the practice that the patient has a good relationship with who could attempt to administer it?
3. Is the patient well known to the practice, do you have information about the person their likes and dislikes, what they are interested in, what you could talk to them about as a means of distraction?
4. Have you contacted family members to see if they can support the patient to the practice?
5. Have you tried to use other forms of communication to help them understand why it is important, i.e. pictures and videos?
6. Have you attempted to use the nasal spray off label as a reasonable adjustment? This is indicated to people with a learning disability in the Public Health guidance where a needle would cause them great distress. Please see link below.
7. Have you contacted your identified health promoter for your practice to see if they can offer any additional support?

https://www.gov.uk/government/publications/inactivated-influenza-vaccine-information-for-healthcare-practitioners - see page 14

NHS
Sunderland
Clinical Commissioning Group

Northumberland, Tyne and Wear NHS
NHS Foundation Trust

Sunderland Flu Plan – Learning Disabilities Community Treatment Team and Primary Care **Appendix 7**

Action	**Progress, comments and further actions**	**Who / when**
Information sharing to take place at TITO event in September. Handouts to be given to practices in regards to the support they can receive from the CTT for Learning disabilities.	Completed	Ashley Murphy – Primary Health Facilitator. Linda Reiling – Specialist Learning disability and Mental Health commissioner. Sept 2016.
A meeting to be held with Senior Team at CTT to discuss how we can support the administration of flu immunisation too hard to reach groups.	Completed in Oct 2016. Ashley to complete the flu plan and circulate Ashley to liaise with Carole Rutter, Matron in NTW to access further flu training for nurses on the CTT. Identified nurses to access this training are: **Carole Green, Maria Foster, Shaleen Mercer and Lisa Plant. Amanda Hunter up to date.** Ashley to write guidance notes to be given to IRS (Initial Response Team) so they are aware of the offer of support from the LD team and know how best to direct referrals. It was agreed that no flu clinics would be scheduled but a reactive approach would be applied in the short term until we have a better understanding of the demand from primary care. It was agreed that Maria would clarify if Rose Lodge have a plan to ensure all of their patients receive their	All to be completed by Mid Nov 2016 Ashley Murphy. Ashley Murphy. Carole Green.

	flu immunisation. Ashley will email all locality practice managers again with a copy of this action plan and a reminder of what is available from the CTT Learning disability Team in regards to supporting the winter plan for people with learning disability.	Maria Foster.
Health Promotion Team will visit all of the GP practices which they have been allocated too. The purpose of the visit is to meet with Practice Manager or delegated person and establish from the learning disability register who may require support to have the flu immunisation. The practice will need to contact these individuals by telephone and find out if they have their consent for the health promoters to contact them directly to offer support.	The Health Promoters have now started to carry out these meetings and are waiting for the practices to inform them when they have contacted the patients and if support is required. This is only for patients who would not ordinarily access their practice and where all efforts have been made previously from primary care to engage with them.	Graeme Fergurson – WEST Emma Reid – WASHINGTON Helen Wharton – COALFIELDS AND NORTH (Southwick, Redhouse and Castletown, Monkwearmouth) Margaret Mather – NORTH (Fulwell, Roker, St Bedes) and EAST Overseen by Ashley Murphy – Primary and Secondary Health Facilitator Team Lead. Jen Burn – Primary Health Facilitator. Ongoing between October and January.
Health Promotion Team will obtain NHS England Accessible FLU POSTERS and display in CTT LD Reception and main day services. Health Transition team will obtain same and display in special schools when visiting.		To be completed by end of Nov 2016. Health Promotion Team Sam Lynn, Hayley cook and Kristy Barkes.

Communication needs to be increased in relation to patients with a learning disability been in a high risk group and are eligible for the flu immunisation programme. Ashley will try to attend a provider's forum meeting in Sunderland to advise managers of residential care homes that they need to support people to attend.	Ashley to contact Claire Quinn for dates of provider forum.	Ashley Murphy Dec 2016.
We need to develop a flu protocol in partnership between NTW Learning disability community treatment team and the GP practices in Sunderland. The purpose of this protocol is to ensure safety of dispensing and administration of the flu immunisation. It will also provide the guidance needed so everyone is aware of their roles and responsibilities.	Meeting scheduled for 31.10.16 Actions from this meeting as follows. 1. Ashley to email Dr Dominic Slowie to seek clarity re administration of nasal spray to adults and ordering issues for nasal sprays if not children. 2. Ashley to ask Dr Dominic Slowie if there is any feedback in relation to systems alerting practitioners that the patient with a learning disability requires a flu inoculation. 3. Ashley and Linda to send an email to locality practice managers for them to further circulate outlining the support they can receive along with the flu protocol we develop and record of flu inoculation. 4. Ashley to draft protocol and send it around for comment.	Ashley Murphy and Locality Practice

Ashley Murphy
Primary & Secondary Health Facilitation Nurse

Hidden Voices of Maternity

Parents With Learning Disabilities Speak Out

August 2015

Prepared by CHANGE PEN *Supported by* NHS England

Hidden Voices of Maternity
Parents with Learning Disabilities Speak out

Table of Contents

Executive Summary

CHANGE AND PEN worked together supported by NHS England to give a platform to the seldom-heard voice of parents with learning disabilities in order to improve the maternity experience for parents with learning disabilities for this group of parents.

Several advocacy organisations felt that the maternity experience for parents with a learning disability was not fully understood and therefore we created an approach to help give these parents the opportunity to share their experience and to be heard. Our approach had 4 elements:

- Over a six week period we invited professionals to take part in an on-line survey.
- From January to April 2015 we held a series of five focus groups with parents with learning disabilities across the country: in Leeds, Coventry, Newcastle, Bath and London.
- To support the focus groups we invited parents across the country to take part in an easy read accessible survey.
- We also undertook some desk research to understand the resources, papers and materials available more widely.

In summary, based on our research we recommend the following (see page 22 for further details):

1. *Ensure each CCG locality area has an antenatal and postnatal care commissioning pathway for parents with Learning Disabilities – or create a National guidance*
2. *Provide training for professionals (social workers, midwives, health visitors and receptionists) to improve communication – empathy, respect and understanding (e.g. LD is not MH)*
3. *Parents to have access to a trusted professional throughout their experience – having their phone details for direct access*
4. *Establish a visible lead in a provider organisation whose role is to support learning disabilities as opposed to mental health or other area*
5. *All parents should have access to a local parent support session – if they want it – focussed on parents with learning disabilities if possible*
6. *Commission peer support (buddy) that is provided via local community based services with timescales dictated by the parent e.g. NCT, third sector*
7. *Option to access easy read materials – midwife to know they are available and offer the option*
8. *Social workers to follow health and make resources easy read now – use NHS England accessible information standard as the lever*
9. *Commission and create local support groups for parents with learning disabilities. Explore who will run these and how they will be managed and funded*
10. *Provide support for parents who do lose the care of their child – there is a system-wide lack of compassion and understanding at this tragic stage*
11. *Commission and provide specific services for fathers who have a learning disability as they reported they felt excluded from existing services and valued peer support*

Resources we found during the project have been included and will be made available on our website. We hope that we will add to this as an ongoing resource. Two areas worthy of further investigation are:

- *more extensively and systematically audit the resources that are in use today and make these widely available - who is using/ not using and why and what are the barriers*
- *explore more widely examples of what is working well and share these – for example where are the parenting groups and what do they do, what other examples of good practice are in place and where*

We have written this report in a simple informal style, co-working with a mum who has a learning disability. It is also available in an easy-read accessible format.

Introduction and Background

Introduction

CHANGE AND PEN worked together supported by NHS England to give a platform to the seldom-heard voice of parents with learning disabilities. The partners worked in collaboration to gain a better understanding of the maternity experience of care for parents with learning disabilities. The end goal of the work is to support both commissioners to ask the right questions of their service providers and service providers themselves in this important area in order to improve the maternity experience for parents with learning disabilities.

CHANGE is a national human rights organisation led by disabled people. CHANGE employs people with learning disabilities to co-lead and work alongside a non-learning disabled colleague for an equal salary. People with learning disabilities at CHANGE use their expertise to educate health and social care professionals to improve their practise. CHANGE supports people with learning disabilities to consult peers and lead projects to tackle discrimination and participation in society fully as equals.

PEN is a not for profit organisation whose ambition is to recognise, celebrate and share what is working well in the experience of care. PEN has written a series of reports to highlight the great work in the maternity experience of care, children's and young people's services and the experiences of families with children who are long term ventilated, amongst others.

Background

Several advocacy organisations felt that the maternity experience for parents with a learning disability was not fully understood and therefore we created an approach to help give these parents the opportunity to share their experience and to be heard.

Learning Disability is defined as "a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence); with a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development". (Department of Health, *Valuing People* 2001)

A learning disability affects the way a person understands information and how they communicate. This means they can have difficulty:

- understanding new or complex information
- learning new skills
- coping independently

A learning disability can be mild, moderate or severe. Some people with a mild learning disability can talk easily and look after themselves, but take a bit longer than usual to learn new skills. Others may not be able to communicate at all and have more than one disability.

A person with an IQ of less than 70 can be diagnosed as having a learning disability. CHANGE advised that for parents usually their IQ will be above 70 and you rarely find a mum whose IQ is below this.

Our approach embraced the fact that people with learning disabilities are unique individuals with their own likes and dislikes, history and opinions, and have the same rights as anyone else (RCN, 2013).

There is a huge range in estimations of the prevalence across the UK, however, The British Institute of Learning Disabilities (BILD) estimates that 1,198,000 people in England have a learning disability i.e.2% of the population. (Feb 2011). This is complicated – not everyone knows they have a learning disability, and not everyone wants to be "labelled".

There has also been a shift in people's attitudes to this group, however, the change is slow and many people still feel "cared for" rather than "supported with".

According to Best Beginnings around 7% of adults with a learning disability are parents. In reality most have a mild to borderline impairment, which may make it difficult to identify them as usually they will not have a formal diagnosis. Often professionals do not want to ask and not all parents want to be asked.

In the maternity setting there is still a very long way to go for this group – who feel marginalised and discriminated against. Many parents with learning disabilities face stereotyped beliefs that:

- they could never be good enough parents
- that any parenting difficulties are automatically linked to their learning disability without considering other environmental or social factors.

Estimations vary but it is thought that between 40% and 60% of parents with a learning disability do not live with their children. According to Best Beginnings the children of parents with a learning disability are more likely than any other group of children to be removed from their parents' care.

Experience shows that some women with learning disabilities may avoid maternity care because of:

- lack of confidence
- negative staff attitudes
- lack of clear explanations of what is going on
- inaccessible leaflets
- fear of the involvement of social services

This information was sourced from Best Beginnings and our work supports this view.

We saw evidence that supported the view that parents with a learning disability can improve their parenting skills with additional support tailored to their needs – this was particularly evident in our focus group in Bath. For example childcare skills can be taught through behavioural modelling, using visual manuals and audiotaped instructions, and using simple behavioural instructions. Parents learn more effectively where they are given praise and feedback, and where complex tasks are broken down into simpler parts.

Parents with a learning disability face extra scrutiny of their parenting ability, but receive inconsistent advice from different professionals on what constitutes good parenting. They feel they are often told what NOT to do but receive insufficient guidance on what TO do.

> *"I felt like I was invisible and not being listened to."*

Parents with a learning disability may be reluctant to ask for support with parenting issues because of fears that this will raise child protection concerns. Many will have already had a previous child removed into care. Some parents will not be eligible for support from adult learning disabilities teams because their learning disability is not severe enough to qualify.

Researchers at the Norah Fry Centre at Bristol University – a leading centre of research on services for learning disabilities – estimate that parents with learning disabilities are up to 50 times more likely to be involved in care proceedings.

What We Did

Professionals Survey

Over a six week period we invited professionals to take part in an on-line survey. In this survey we asked a series of questions to help us understand the maternity experience in general and specifically for parents with learning disabilities. 107 professionals took part. Their comments and feedback are included in this report.

Focus Groups

From January to April 2015 we held a series of five focus groups with parents with learning disabilities across the country: in Leeds, Coventry, Newcastle, Bath and London. The first focus group in Leeds was a Steering Groups giving us guidance on how to shape the subsequent four sessions. We also spoke with some relatives of parents with a learning disability in two of the sessions.

Mothers and fathers with learning disabilities were invited and in total we met 34 parents from across the country. Some have their children living with them, many did not; some brought their children with them! For some their child was yet to be born (and one left to go to the maternity unit!) and for some their child was now an adult.

In each focus group we invited parents to share their experience and their hopes with us. In many of the groups we were joined by interested professionals e.g. student midwife, local midwife, student social workers, other researchers and by advocates.

Parents seemed to really value the opportunity to come together and realise they had so much in common – these were sharing and emotional conversations – tissues were needed on many occasions. Some already knew each other but others did not, but for all the connection was powerful.

The key findings from the focus groups are covered later, but in summary there seemed to be a huge variation in the experience for parents across the country – there are pockets of great practice where parents feel supported – both those who have kept their child and those who have not, but more often they felt the "system" had judged them and treated them unfairly.

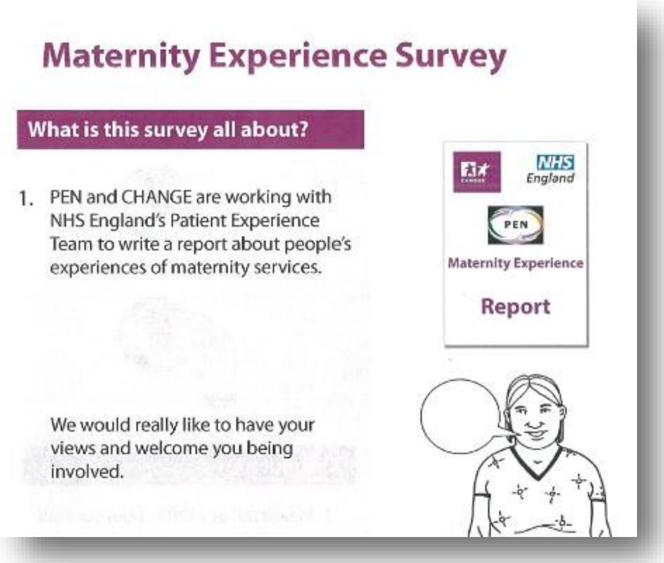
Where parents felt supported they had access to quality advocacy services by advocates who they trusted, professionals (midwives, nurses) who understood them and their needs and good local providers. Where they did not the opposite was true.

What became clear is that when parents do "lose" their child i.e. have them taken away there is a system-wide lack of compassion and understanding. Ultimately this is a devastating situation for any parent and no "bereavement" type support seemed to be available for these parents.

Parents often blamed themselves and found it difficult to get answers that they understood.

Parents Survey

To support the focus groups we invited parents across the country to take part in an easy read accessible survey. We have included the feedback from these parents in the report. These surveys reinforced what we heard in the focus groups.



Maternity Experience Survey

What is this survey all about?

1. PEN and CHANGE are working with NHS England's Patient Experience Team to write a report about people's experiences of maternity services.

We would really like to have your views and welcome you being involved.

Desk Research

We also undertook some desk research to understand the resources, papers and materials available more widely. These have been included as appropriate.

> *"I think midwives should be trained in how to deal with people who have learning disabilities because I just feel as though, when someone hears the word disabled or learning disability, people don't understand what it is and just think that you're stupid or label you and treat you as though you don't exist."*

Ladder of Power

In each focus group we discussed a range of people involved in the maternity experience – using a ladder of power. Using this we asked each group to discuss each type of person involved in their experience of parenthood and how much power they felt they had over them as parents and their experience of maternity. Each type of person was added to the ladder depending upon how much power they felt they had – the most at the top of the ladder – the least at the bottom.

As we introduced each new type of person we discussed how the parents felt about that person and why, what their concerns and experiences were and where they placed these people on the ladder of power. Each group ended up with their own ladder of power.

Leeds

Coventry

Newcastle

Bath

London

Using the insights from these focus groups over the page is the typical ladder of power with comments from parents. Where possible have used the words of our parents:

Ladder of Power

Social worker was always at the top: Most parents had a bad experience "as they have the power to take your children off you" Comments ranged from: *"they have all the power", "they decide, you have to prove you are good enough to look after your child"*, to *"mine wasn't that bad" In* many cases parents did not feel they had a reasonable explanation of why their child was taken away. The concept of neglect is a difficult one to understand.

Hospital midwife can be very impactful and in terms of power was often above the Consultant. Feedback was very mixed: For some parents they are *helpful "when I was upset she was there to help"* but most commented they felt judged *"you can't carry your baby – you may drop her", "she removed my baby and would not let me see her", "she assumed I would not want my child"* and *"she kept waking the baby up – I did not know why".* There seemed to be little compassion for parents who they know will lose their child and often they were "skewed and alarmist".

Health Visitor was mixed – some felt they were very powerful others less so. At times they were very helpful*: "she helped me get a nursery place"* or "*she got me safety gates" "I knew she was just a phone call away"* – for others they were not so positive *"I felt the dad was pushed away".*

Obstetrician were rarely reported to be involved but when they were they were quite powerful. The different kinds of Consultants were not understood e.g. Gynaecologist, Paediatrician.

Community midwife was seen as more powerful than the GP- partly because "*they actually come into the home to check you"*. Although feedback was mixed as a rule these were felt to be more sympathetic than the hospital midwife.

Receptionist was more powerful than the GP – they are the gatekeeper to whether you get an appointment or not – for others where they did not have a problem they were close to the bottom of the ladder of power. *"you can tell their attitude on the phone", "I'd like them to listen more".*

GPs "*do not have the power to take children away but do make important decisions"* and overall the parents did not have much to say about the GP. *"I smiled at the doctor but I didn't really understand them – I think I should have really disagreed and made a bigger effort".*

Nurse in GP – parents like to be seen by the same person "*it really matters if they are not the same person. They do not pass information on and I do not like being passed from pillar to post". "Nurses can spout a lot of information – they are proper annoying."*

Advocate – in the majority of cases the advocate was seen as hugely supportive; in a couple of cases the relationship was not working so well. They were seen as an enabler – and for some they wanted *"more advocacy before having the baby – it can be very scary".*

Mum with learning disability was at the bottom – just above the dad in most cases. This is not where they felt they should be - *"the mother should have the most power – she should have a voice".* They felt they were *"treated like they were daft, stupid or a two year old", "they made you feel horrible"*

Dad with learning disability was usually right at the bottom as they *"do not get a say"*. They are often told they cannot come to see their baby being born. The exception was where the relationship was abusive or the Dad was manipulative in other ways. "*The father can walk off and leave the mother with the baby". "If the mother has a LD then social services require an assessment – it is not the same if the Dad has a LD".*

Four additional stakeholders/ groups of people with power were mentioned:

- The families of the parents with a learning disability – their mums and dads, aunts, sisters, who could make the difference between keeping their child at home or nearby – "my parents knew mum and baby had to be together so they moved closer to help us"
- School – who could be supportive or on occasions could be extremely unhelpful – "they called me in over a silly bump on the head"
- Work colleagues – several of the mums found their work colleagues were extremely supportive and helpful giving them useful guidance
- Family Support Workers – some mums had access to these and they were felt to have been very helpful

What We Found - The Pregnancy Experience

In the focus group we asked the parents to describe their experience from the moment they found out they were pregnant until they were at home. We have captured what they said in their words in the following pages across their experience. There are a few great examples of when it is been a good experience, but this is far exceeded by the examples of what has not been a good experience for this group of parents.

Overall the parents felt what worked well were:

- access to the community midwife
- where buddy schemes existed these were well received
- the advocacy provided
- support groups e.g. Georgie Mums, Camden People First

Overall areas the parents felt did not work well were:

- being judged all the time
- attitude of staff
- conflicting information (people telling you different things)
- not supported to breast feed
- if in pain not supported by the midwife
- most Dads did not feel welcomed during birth
- no support when babies taken away
- encouraged to have an abortion without being told why
- ability to get appointments at the GP.

> *"I would like more people to be aware and trained about what a learning disability is so we don't get mistreated and misjudged."*

Before

	When I found out I was pregnant	What happened next	What information was available
☺	"I was very happy when I found out" "I had a pee test and it told me I was one week and a half pregnant" "The pregnancy was unplanned for my first, all other pregnancies were planned" "I have had three pregnancies and have seen the same midwife for all three. She made me feel more relaxed/confident"	"I went to the doctors and was introduced to the midwife" "Barnado's did parenting classes in the home – they were very helpful"	"My mum explained a lot to me – I had people around who could explain things to me"
😐	"I did not find out until I was 6 months pregnant as I was having injections" "I new something was wrong because I had no periods" "I tried several pregnancy tests" "For my second baby I was confused – I still had blood – but knew something was wrong. I felt the baby move at 6months and knew I was pregnant"	"I was nervous going to the doctor" "I had to go to the hospital for ante natal care for my kidneys, and never got to my appointed doctor – I saw different people every time " "The nurse mumbles – she is not English and uses big words I do not understand"	"The book was not easy to read but it did explain. I was showed videos and I went through all the information" "The colour of the uniforms can be confusing" "I can not read or write – pictures work well for me, but I also need someone to explain it several times too"
	"Nervous and worried. As well as having a learning disability I also have cerebral palsy. I wasn't allowed to have my baclofen throughout the pregnancy." "I was very nervous. My disability makes it difficult for me to talk to people"	"My doctor understood my learning disability and I felt I was listened to."	"The midwife was friendly but didn't give me any information, I just looked on the NHS website. I had no ante-natal classes and wasn't informed about them even though I asked."
☹	"I was shocked at being pregnant at 16 years" "Social services did not like the fact that I was living with my partner because he was violent to me" "I felt mortified because I was in a difficult situation with my other children" "I was nervous and scared – I was worried that my child would be taken away"	"Because I was 16 they said I would need extra help" "I felt judged – people kept asking me 'are you sure you want his baby', 'what if it has Downs Syndrome'" "I was bleeding at 11 weeks and had to ring 111 - the midwife did not give me this information" "At 24 weeks I found out I had E. Coli infection in my kidney" "At 25 weeks I got beaten up and went to get checked up"	"I did not have any information" "When I had my second child I forgot all the signs – the midwife assumed I remembered everything"

Birth

	What kind of birth I had	What happened next	What information was available
☺	"I had high blood pressure so I had a caesarean to be on the safe side" "I was offered a caesarean but I wanted to push my baby out so I was given the choice"	"My midwife was really caring, I could not fault her. I would like to have had the same midwife all the way through"	"The consultant explained the caesarean very well" "I got good info off the teen midwife about labour"
😐	"I was told I had to have a caesarean" "I had a natural birth"	"The baby popped out in 9 minutes!"	We went through the birth plan and they explained everything e.g. epidural and we stuck to the birth plan"
☹	"I was treated very badly. I was told I could have a natural birth but then I was told I had to have a planned caesarean. They wouldn't explain why and I was very scared during the caesarean." "They shout at you and treat you like you are daft or stupid, they make you feel horrible!" "Not good – they didn't have time for me"	"I had high blood pressure and the doctors said I was exhausted, the midwives put on my notes I had post-natal depression. When my son was born they took him away for 2 hours and nobody would tell me where he was. I had him for 5 minutes before they took him away." "The midwife shouted and was nasty because I was too tired to push" "The dad was told he could not come to see the baby being born – he was told to go home" "They didn't believe me when I said I was in pain. When I was sick they told me not to mess the floor up" "It came out crying – I was shocked"	"They didn't explain why I couldn't have a natural birth and they didn't explain whether I had exhaustion or not etc. There were no ante-natal classes and I was only allowed to look around the ward the day before the caesarean. I was that scared and shaking they allowed my husband in for the whole caesarean. normally they would have to wait outside first and then come in. I read a bit on the NHS website but it wasn't an easy read and I was still very scared. I was shaking that much with fear I was asked if I was cold." "No one told me how painful it would be" "When it was born at 29 weeks I did not expect it to have arms and legs – I did not understand how babies develop"

Afterwards

	Back on the ward	What happened next	What information was available
☺	“One nurse in the hospital spoke to me horribly, she was very mean. I wanted to walk around and do things because that’s how I am. I have autism.” “The midwife could see I could look after my baby”	“She kept telling me off, until she found out about my disability. then she was very nice to me and a lot more understanding” “I was left on my own”	“Social workers wanted me to be under social services, but the midwife said I was OK to go home”
😐	“I did not want to wake her and feed her but I was told I had to”	“They were much more helpful at home than at hospital” “Why did they prick his feet?” “It took more than 2 hours to do the checks before I was allowed home”	“There were no clear rules – every one said something different – it was very confusing” “I have to read the information five times to understand” “I had to teach my partner to feed him, change his nappy etc.”
☹	“Why are some midwives and nurses so pushy and keep waking you and the baby up?” “They snapped ‘When did you last feed that baby? Did you write it down in the rota?’” “I got told off – it felt really unfair” “I felt very small – they looked down on me” “The midwives kept telling me he would be removed after 4 days”	“The father was not allowed in” “They told me I had a choice - stay with my partner and lose my baby or leave my partner and keep my baby” “I felt they were treating me differently – I was told I would drop her – other mums were allowed to carry their babies” “They made me feel like the baby was not mine – it was horrible!	“No one showed me how to bottle feed” “I was not supported to use the knowledge I had so I lost confidence”

Breastfeeding

	Breastfeeding	What happened next	What information was available
☺	“I had a good experience with breast feeding” “I did not think I could breastfeed – I have epilepsy so I thought I couldn’t because of the medication, but the community midwife said I could”	“The midwife helped me to latch on and showed me how to feed”	“She wrote a good report about me” “The specialist LD Nurse took photos and showed me these photos so I could understand – how to hold, how to feed etc.”
😐	“I had a caesarean so was never told about breastfeeding” “I did not feel confident or comfortable to breastfeed”	“I wanted to breastfeed but I couldn’t” “I had problems breastfeeding – I did try but I got very sore”	“I was taught how to bath the baby, but not how to breastfeed it”
☹	“Mums with a learning disability are often not supported to breast feed – it is seen as a bonding exercise so it in not encouraged because they may not keep the baby” “The baby was taken away and two days later they sent someone to help her express – the family had to deal with it”	“I felt useless because I tried and tried and always felt in the wrong”	

When something goes wrong

	When something goes wrong	What happened next	What information was available
☺	"The nurses were nice to me in the hospital I was in there for 4 days because of complications and I was poorly"		
😐	"When we found out our son's bowels were growing outside his body they walked outside and someone came back and looked at the scan."	"They walked out again leaving us worried. They then pushed us into the reception until someone explained. We were crying."	"Knowing more info about my son's condition. I had to look on my PC to find out. They told us to leave and come back in a couple of days"
	"She saw the baby had fits and she listened to me"	"She explained about the blood tests and what they were for"	
☹	"I didn't understand when he got jaundice what was going on – there were tubes out of his nose and everything!"	"There as no explanation of what the infection was – only that it could kill me, my baby or both"	"When you have a premature baby why can't you stay in the same room as them? This was not explained to me"
	"I got an infection in my placenta and needed a C-section"		
	"They said I couldn't go home – I needed to be assessed"	"It was very stressful. I have to pack with a new baby- and go into a new environment and I was watched on camera 24 hours. Nothing I did was right"	

At home

	Back at home	What happened next	What information was available
☺	"She was very nice and helpful" "Social worker now is good - she understands and makes sure I know when I have done a good job"	"My baby has an allergy to milk – she got me some other milk"	"I am a look and learn person – she drew pictures and left them on the fridge e.g. sterilising"
😐			
☹	"There was no hand over from the hospital midwife to the community midwife – they do not share information" "Social services said I was too affectionate with my babies and too protective" "They just took my child away – and did not give me any support or counselling. I was told to go to the GP"	"My child lived with us until he was 3, then he was removed. Then they moved and I lost contact for 6 years" "I did not understand what was happening – we went to court" "They use neglect as an excuse in court" "They put me on depression tablets – I blamed myself" "They took my daughter away on 5th November – I was saving up for Christmas"	"No one explains what neglect is – I still do not really understand why they were taken away"

Other Observations and Concerns

During our conversations we heard of other areas of concern/ observations:

1. **Judged** – When speaking with the parents what became clear is they experience much of what other parents experience, the same concerns, the same questions and emotions, but this is often amplified for the parents with a learning disability as they feel judged at every point – they have to prove they are good enough to be a parent; other parents simply do not have this external additional pressure

2. **Care act** – there is a perception that people with a mild disability will no longer have access to their much needed advocacy support

3. **Breadth** – the parents we met represented the full breadth of social circumstances with many examples of rape, abuse, paedophile predators, teenage pregnancies, multiple fathers, through to parents in long term loving relationships

4. **Difficult births** – it appeared that there were more caesarean births and difficult births e.g. premature, complications etc. than is the norm, but we do not have statistical data to support this

5. **Empathetic** – this is an audience who are highly empathetic in many cases, and so extremely tuned into nuances and attitudes

6. **Challenges** – often these parents themselves have children with learning disabilities and indeed their own parents have a learning disability making their circumstances more challenging and requiring the right support

7. **Abortions** - CHANGE hear a lot about pregnancies where abortion is recommended but not fully explained

8. **Bereavement** – when their baby or child is taken away there seems to be a total lack of support – this for many is like a bereavement and they have no coping infrastructure to support them. These were incredibly difficult and emotional conversations as understandably parents find this a difficult topic to discuss

9. **Social worker** – the relationship with the social worker was rarely a good one – making this a stressful topic for all – one parent had to leave because they were so upset. This is hard to address as their role is a critical one but in its current approach is not working for the parents

> *"I am always fearful that they will take my child away."*

Professionals Survey - Examples of what is working well

Below are some examples shared in the professionals' survey of what is working well in their organisation. This is taken from the survey that 107 professionals took part in. Interestingly the key themes highlighted by the professionals mirror those raised by the parents. One question asked specifically about examples of good practice related to the maternity experience for parents with learning difficulties or other vulnerable, hard to reach or disabled families. All the examples put forward are included below. Full results from this survey are available in a separate report: ***Celebrating the Best of the Maternity Experience of Care with a focus on parents with learning disabilities*** available from PEN.

Good use of Multi-disciplinary working using BSL Interpreters, Adult SW, Hospital staff to allow extra explanation for a profoundly deaf woman with LD who requires Gynae Surgery. Used Hospital communication book to explain what would happen after surgery.

We have 2 public health midwives working in Knowsley who provide care to vulnerable women which includes women with learning disabilities and other vulnerable groups. They link in with many services to provide tailored care e.g. obesity pathways and links with slimming world and other groups.

We did work very closely with all agencies involved with a patient recently who had a learning disability and had frequent multiagency meetings throughout her pregnancy and following delivery which enabled us to all support the family more effectively. We aim to make this the norm in all cases in the future. This lady did have a very effective support system already in place.

1. Traveller families Invited by family to record their experience as users of the service. This was then shared with providers. This reflected the following insight - mainstream services appear too wary of large groups attending the unit in support of their family member and are struggling to provide the reception desired. A work in progress.

2. Young mums and mums to be Invited personally to attend a community event in a local church in the centre of Chester city to be pampered free of charge. Nails, make up etc . A one stop shop was created in this pop up session for one afternoon. The young mums met future staff and signed up to groups such as parenting sessions; one agreed to retry to lactate with her baby following contact with breastfeeding Hv specialist.

The Hospital has a dedicated Safeguarding Midwifery team.

> *"I feel powerful because I have kept my children and I have worked hard to keep them."*

We have a number of initiatives for vulnerable families including

1. Case loading of women in prison including safeguarding, pregnancy support and scanning at the prison, mother and baby unit in prison with parenting skills taught. Two safeguarding midwives caseload the prison women and babies.

2. Perinatal Mental Health Midwife with a focus on community based care and liaison with mental health agencies.

3. Birth Reflections Service for women and partners suffering following difficult birth, birth trauma, depression and needing counselling.

4. Bereavement midwifery team - giving support follow stillbirth and pregnancy loss.

5. Enhanced postnatal pathway for women and vulnerable families requiring extra support, help, advice and observation.

If any women has a disability she will be offered a home visit to assess and plan for any additional needs she may have with regard to maternity care.

Mainly through individual care plans and working with the services already in place for the mother.

Mainly the community midwife is aware of a family's problems and will endeavour to secure adequate support for them through the appropriate channels. These can sometimes be difficult to access due to communication with the LD team.

We have a dedicated team of 3 specialist midwives who care for the most vulnerable 2% of our local population offering enhanced, individualised care to meet each family's needs.

During time on Community was instrumental in organising & running AN class for vulnerable mothers i.e. No English, disabled, teens, anyone in need. Set up leaflets in other languages in conjunction with council run assoc. Teenage pregnancy Midwife & team. Specialist Midwives in all vulnerable areas.

I was a part of the recent care of a woman with a learning disability in my position as Midwife For Long Term Conditions. I made sure I was available to see her when she came into hospital for antenatal appointments, so she always saw a familiar face. I worked with the woman, her partner and mother to produce an individualised plan of care to ensure her experience of our maternity services was a positive one.

Myself & my colleague run a service of extra advice & support to young people, which includes those with learning difficulties.

Development of pathway-aids staff in directing to appropriate care & support which improves service user's experience. We have a 'One stop antenatal clinic' for those with substance abuse We work closely with the following working with vulnerable groups:- NSPCC and alongside their 'Baby steps programme' Integrated Care Pathway (ICP)- a preparation for parenthood programme in the Children Centres Involved with Family Link workers (FLAN). Work with the Family Nurse Partnership Programme (FNP) Bradford about to start the 'Better Start Programme' Ties with 'Here we are group', newly started 'Birth Choices group' and work closely with the Bradford & Airedale 'Maternity Partnership' group. 1:1 Parent Education is offered with Specialist Midwife in Parent Education together with HFN/support worker to prepare those with LD or any specific needs for the rest of their pregnancy, forthcoming birth & becoming parents. Visits to Labour Ward, Birth Centre & wards all offered & undertaken to help reduce anxiety of coming into a new/strange place. Consideration given to involving a doula for birth support & possibly post birth.

Community midwives routinely ask about learning difficulties / disabilities for all women and refer to the Specialist Midwives for additional support and planning. Joint pregnancy and birth planning with appropriate agencies as soon as possible to ensure appropriate support provided to women and their families to meet their individual needs. All vulnerable, hard to reach and women with disabilities are referred as above and pregnancy and birth planning undertaken if appropriate for the individual.

We have a Disability action and awareness group which has service users and staff as members. We have a folder available for each midwifery team with resources available. We employ a Disabled Public Health Midwife

Both parents would stay in the postnatal ward to ensure parenting skills etc. resulted in the family being equipped to take baby home. We have baby showers for hard to reach parents. Planning grandparent event in hard to reach areas.

We have a team of midwives providing additional support for women from vulnerable groups, providing continuity throughout the pregnancy episode. This team link closely with safeguarding team and social care services.

Mother with Friederichs Ataxia wheelchair bound care provided by Vulnerable team midwife in her area. Birth planned for another site with antenatal birth plan multi-disciplinary meeting to plan birth and postnatal care in hospital. Breastfeeding support and parenting support planned and implemented after the birth. MDT discharge planning meeting held with handover of care back to original vulnerable team midwife. Postnatal care at home.

What We Would Change

We asked the parents to consider what they would do to change the experience. Clearly every parent's experience is different as is what they are looking for from their experience, however there are some core areas that they did put forward:

Process improvements:

- One point of contact throughout the process – someone we trust and can understand
- Buddy scheme – with a parent who does not have a learning disability
- Communication – ensure information is shared more effectively across the different professionals
- Parenting classes – offer parenting classes that cater for this group of parents

People improvements:

- Provide training – of how to work with parents with a learning disability (both midwives and social workers)
- Attitude and behaviour – particularly people on the wards and in the GP practice
- Communication – many parents struggle with literacy or have a short attention plan so provide resources that will help e.g. easy read/ DVDs/pictures and be happy to repeat important messages

Physical improvements:

- Cleanliness – ensure wards are hygienic
- Temperature – make sure wards are not too cold
- Uniforms – colour of the uniforms can be very confusing

> *"It feels like a crime to have a baby – people who drink and take drugs have babies, why shouldn't a person with a learning disability have a child?"*

Recommendations and Next Steps

From all of this we have pulled together some key recommendations and next steps. We know some of these may not be easy, and we do not know how some of this may be achieved, however, these are the key areas coming out of our work with both parents and professionals:

1. **Strategy:** Ensure each CCG locality area has an antenatal and postnatal care commissioning pathway for parents with Learning Disabilities – or create National guidance. Providers also to focus on Learning Disabilities in their maternity strategy. For example Leeds has a 5 year maternity strategy where parents with a learning disability are identified as a key group with a pathway planned and a key focus for the next 5 years.

2. **Training:** Provide more widely available training for professionals (social workers, midwives, health visitors and receptionists) to improve communication – empathy, respect and understanding (e.g. LD is not MH). For example it is felt that Children's social workers do not have specific training in this area. It was felt that by providing training to students it would start to cut though the stigma. Professionals comment they are not consistently offered specialised training in this area.

> *"Treat me properly, treat me right, be nice"*

3. **Continuity:** Parents to have access to a trusted professional throughout their experience – having their phone details for direct access. This continuity was seen to work well for teenage pregnancies and could be extended to all parents with a learning disability; some Trusts already provide this. Clearly this will only work where the professional is trusted and supportive. Ideally have specialist learning disability midwives or liaison nurses. A key issue is that professionals do not always know who may have a learning disability and some parents may not wish to admit it to avoid the stigma; good questions to ask may be "what support are you going to need?" and sharing some easy read information and asking "would you like more information like this?"

4. **LD Lead:** Have a visible lead in a provider organisation whose role is to support learning disabilities – similar to the Mental Health lead which is perceived to work well. Some Trusts have implemented this but it is not the norm.

> *"They talk to you like you are stupid, or a child and they undermine you"*

5. **Parental Support:** All parents should have access to a local parent support session – if they want it – focussed on parents with learning disabilities if possible. This includes the fathers who often feel excluded. In one area Barnado's offered parenting classes in the home and there were felt to be very helpful.

6. **Buddy:** The option to buddy with another parent – peer to peer parenting - was seen to have been working well in one area, although the funding has subsequently been removed for this. It was felt this would be one of the most powerful support for this parent group. Moving forwards commission peer support that is provided via local community based services with timescales dictated by the parent e.g. NCT, 3rd sector.

7. **Accessible information:** Option to access easy read materials – midwife to know they are available and offer the option. Ensure these are at the right level – not too simplistic or babyish. Materials already exist and are relatively inexpensive to purchase. One midwife had successfully supported her parent by taking pictures for example of how to hold the baby and how to feed it, and sharing these. Provide templates of easy to read letters for professional to access – sometimes parents receive letter they do not understand and so miss important appointments and are perceived to be irresponsible – whereas they simply did not understand. Offer more accessible information on key facets e.g. can you afford this baby, premature babies, when baby is unwell, children > 5.

8. **Information Standard for social workers:** Social workers to follow the lead of health and make resources easy read now – use the NHS England Accessible Information Standard as the lever.

9. **Support groups:** Commission and create local support groups for parents with learning disabilities. Where support groups are in place these work well e.g. Geordie Mums and Camden People First. In some areas the Parents came together for the first time e.g. in Coventry and Bath and it was clear the parents valued the opportunity to meet other parents in similar situations. Explore who will run these and how they will be managed and funded.

__Philipa Bragman of CHANGE__ says learning disabled parents often feel they are put under unfair scrutiny, driven by an assumption that if they have a learning disability they cannot be a good parent.

"These parents are often judged in ways that other parents are not," she argues.

"They are the only group with a perceived risk from the start. They go through a process where they have to prove they can parent rather than an assessment of what support they need to parent. They feel they are set up to fail," she says.

Bragman believes many of these issues stem from miscommunication between parents and practitioners.

"The parents are often seen as being difficult when they can't quite understand what is required of them. There is an assumption when communication breaks down that they don't care, but very few parents are deliberately difficult."

10. **Loss:** Provide support for parents who do lose the care of their child – there is a system-wide lack of compassion and understanding at this tragic stage. Simple things like moving the Mum from maternity to another ward when their baby has been removed to more complex bereavement type counselling.

11. **Fathers:** Commission and provide specific antenatal and postnatal services for fathers who have a learning disability as they reported they felt excluded from existing services and valued peer support.

Acknowledgements

We would like to thank CHANGE and Catherine Carter in particular for co-working with Ruth Evans – it's been fantastic to get to know you

We'd also like to thank the parent groups who took part:

CHANGE
Grapevine
Geordie Mums
Your Say Your Advocacy
York People First
Speak Up Rotherham
Camden People First

Thanks also to all the professionals who took part in our survey and to the parents who completed their survey.

And of course thanks go to NHS England who have funded this opportunity to hear some of the hidden voices, allowing parents with learning disabilities to speak out.

Mums with Learning Disabilities

I've an IQ of less than 70 and I'm going to be a mum,
Take some time to get to know me – I'm not the only one,
Stuff that really helps me is continuity of care –
seeing a friendly midwife, someone who really cares.
Getting information that is accessible for me,
it gives me a bit of power so I'm a partner – that's the key!
Yes, breastfeeding may take a bit more time, but it's worth the fuss!
Challenging the stigma, really is a must!
So next time when you have the privilege to care
for a mum who's got LD –
please invest the time and care…..

Appendices

Word Bank

PEN co-worked with CHANGE and during this process we have prepared a word bank of complex words:

Focus Group: group of people who are invited to take part in the research

Gynaecologist: special doctor who looks after women

Insight: useful information

Obstetrician: surgeon that delivers the child

Paediatrician: special doctor who looks after children

Qualitative Research: research that helps understand issues

Quantitative Research: research that involves lots of people

Survey: a set of questions that is used in research in a questionnaire

Resources

Please find below lists of various resources we have found as part of this project. This is by no means exhaustive and would love to hear of any additional examples to share. Please send these to r.evans@patientexperiencenetwork.org These will be hosted on our website: www.patientexperiencenetwork.org under Resources.

List of advocacy services

During the process we have created a list of advocacy services and other support groups. At the time of writing there are 193 entries. If you would like access to this list please contact Catherine Carter at CHANGE or Ruth at PEN.

Papers

British institute of Learning Disabilities (BILD) Fact Sheet: Learning Disabilities Ken Holland Feb 2011 Useful fact sheet about learning disabilities

Community Care: Parents who feel set up to fail Louise Hunt September 2011 A Kent project is proving that proper support for parents with learning disabilities can lead to fewer children being taken into care

Department of Health: Valuing People 2001 This is the first White Paper on learning disability for thirty years and sets out an ambitious and challenging programme of action for improving services

Department of Health Valuing People Now: Summary Report March 2009 - September 2010 This report shows how providing clear and transparent information can enable local people to look at progress and improve services at a local level.

RCN Learning Disabilities A review of learning disabilities and repository of papers and references.

Resources for Parents

Baby Steps Programme at NSPCC:
http://www.nspcc.org.uk/services-and-resources/services-for-children-and-families/baby-steps/
Baby Steps is an NSPCC ante-natal programme helping vulnerable parents cope with the pressures of having a baby.

Best Beginnings:
https://www.bestbeginnings.org.uk/parents-with-learning-disabilities and their Baby Buddy app which helps and supports mothers by having information in bitesize chunks, with simple and clear language so that a mother with a reading age of 11 can understand.

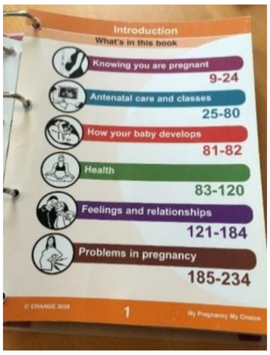
CHANGE:
www.changepeople.org have a series of resources available in easy read format. These include:

- My Pregnancy, My Choice
- You and Your Baby 0-1
- You and Your Little Child 1-5

Photographs from these resources are shown below:

The Court and your child:
when social workers get involved
easy words and pictures

wake smith
Barristers at BankHouse



Introduction
What's in this book
Knowing you are pregnant
9-24
Antenatal care and classes
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How your baby develops
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Health
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Feelings and relationships
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My Pregnancy My Choice

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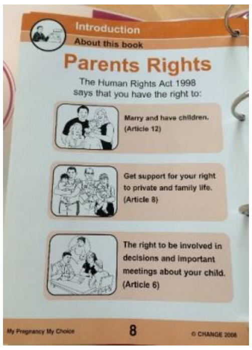

Introduction
About this book
Parents Rights
The Human Rights Act 1998
says that you have the right to:

Marry and have children.
(Article 12)

Get support for your right to private and family life.
(Article 8)

The right to be involved in decisions and important meetings about your child.
(Article 6)

My Pregnancy My Choice
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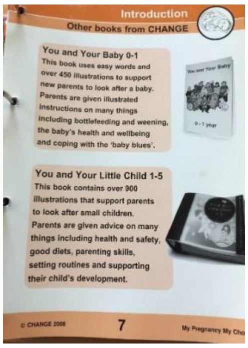

Introduction
Other books from CHANGE

You and Your Baby 0-1
This book uses easy words and over 450 illustrations to support new parents to look after a baby. Parents are given illustrated instructions on many things including bottlefeeding and weening, the baby's health and wellbeing and coping with the 'baby blues'.

You and Your Little Child 1-5
This book contains over 900 illustrations that support parents to look after small children. Parents are given advice on many things including health and safety, good diets, parenting skills, setting routines and supporting their child's development.

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My Pregnancy My Cho


Introduction

About this book

The aim of My Pregnancy, My Choice is to provide an easy words and pictures guide to pregnancy and birth.

It will support parents with learning disabilities and parents who find reading hard, to make choices about their pregnancy.

Staff with learning disabilities and their co-workers have taken ideas and guidance from parents with learning disabilities and professionals to make this book.

We know that an accessible book is something that parents have wanted for a long time.

3


Word Bank

Hard words made easier

405


Word Bank

Hard words made easier

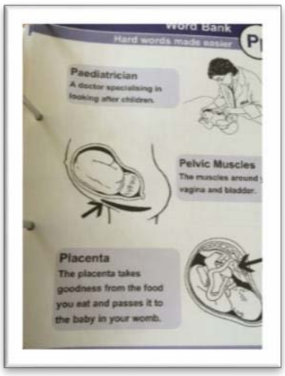
Obstetrician

A doctor specialising in pregnancy and childbirth.

Obstetric Physiotherapist

A person who specialises in problems during and after pregnancy.

420


Word Bank

Hard words made easier

Paediatrician

A doctor specialising in looking after children.

Pelvic Muscles

The muscles around vagina and bladder.

Placenta

The placenta takes goodness from the food you eat and passes it to the baby in your womb.

Shared Lives South West:
http://sharedlivessw.org.uk/about-us/ - a Charity that pairs adults with learning disabilities or, sometimes, dementia, with trained people who are committed to the idea of sharing their homes, families and lives, either short or longer term

Sure Start Project:
http://www.nidirect.gov.uk/sure-start-services a government programme which provides a range of support services for parents and children under the age of four, who live in disadvantaged areas across Northern Ireland.

Resources for Professionals

This is my

Hospital Passport

For people with learning disabilities coming into hospital

My name is:

If I have to go to hospital this book needs to go with me, it gives hospital staff important information about me.

It needs to hang on the end of my bed and a copy should be put in my notes.

This passport belongs to me. Please return it when I am discharged.

Nursing and medical staff please look at my passport before you do any interventions with me.

Things you must know about me

Things that are important to me

My likes and dislikes

- Being a Parent, Buckinghamshire Interagency Protocol, working with Parents with Learning Disability

- Hospital Passports are widely used (see PENN2013 Northumbria NHS Foundation Trust – Joint North Tyne Hospital Passport

- Inclusive Support for Parents with a Learning Disability

- Inequalities Sensitive Practice Initiative, Maternity pathways – Women with Learning Disabilities Greater Glasgow and Clyde

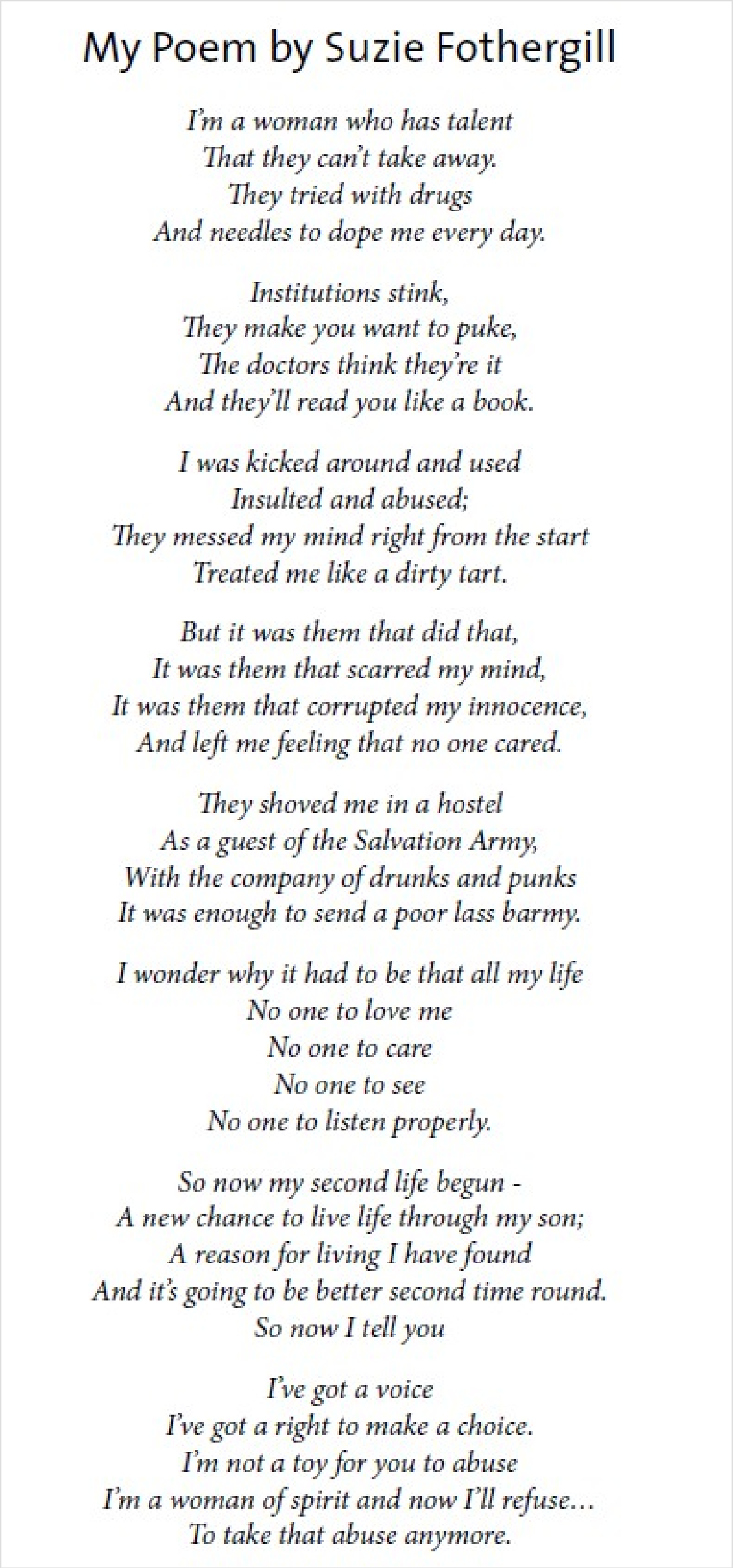
- **Kent Project:**
  http://www.communitycare.co.uk/2011/09/23/supporting-learning-disabled-parents-to-keep-their-children/ – an interesting project in Kent Valuing Parents Support Service that is working hard to ensure more children stay at home with their parents

- Leeds Maternity Strategy 2015-2020 pages 5 and 23 specifically focus on parents with a learning disability

- **Norah Fry Research Centre at Bristol University:**
  http://www.bristol.ac.uk/sps/research/centres/norahfryresearch/ who are a leading national centre of excellence for applied social research and teaching, making a positive difference to the lives of disabled people. Their website has some easy read resources

- Parenting with learning disabilities – Response and Recognition – Department for Education Parents with Learning Disabilities in Bristol - A brief overview of local evidence: Lesley Russ: Public Health: Bristol City Council lesley.russ@bristol.gov.uk

- What Works for Parents with Learning Disabilities? – Summary - Susan McGaw, 2000 Barnado's



My Poem by Suzie Fothergill

I'm a woman who has talent
That they can't take away.
They tried with drugs
And needles to dope me every day.

Institutions stink,
They make you want to puke,
The doctors think they're it
And they'll read you like a book.

I was kicked around and used
Insulted and abused;
They messed my mind right from the start
Treated me like a dirty tart.

But it was them that did that,
It was them that scarred my mind,
It was them that corrupted my innocence,
And left me feeling that no one cared.

They shoved me in a hostel
As a guest of the Salvation Army,
With the company of drunks and punks
It was enough to send a poor lass barmy.

I wonder why it had to be that all my life
No one to love me
No one to care
No one to see
No one to listen properly.

So now my second life begun -
A new chance to live life through my son;
A reason for living I have found
And it's going to be better second time round.
So now I tell you

I've got a voice
I've got a right to make a choice.
I'm not a toy for you to abuse
I'm a woman of spirit and now I'll refuse…
To take that abuse anymore.

From ***No Going Back***
Forgotten Voices from Purdhoe Hospital
Written by Tim Keilty and Kellie Woodley

For further information please contact:

Ruth Evans at PEN
r.evans@patientexperiencenetwork.org

or **Catherine Carter at CHANGE**
catherine@changepeople.org

Supporting people with learning disabilities through flagging within the Bowel Cancer Screening Programme

Project/process evaluation

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Bowel Cancer Screening Programme, North East Hub
Helen Thompson
South Tyneside Community Learning Disability Team

November 2016

Contact details

For further information on the project, it's set up and outcomes please contact:

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1.0 Introduction

People with a learning disability (PWLD) have poorer health and are more likely to die at a younger age than the general population[i] [ii]. Their uptake of cancer screening is much lower and they are at a much higher risk of gastrointestinal cancer[iii]. Bowel screening was identified through the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) as being particularly problematic[iv].

The North East and Cumbria Learning Disability Network, with support from the ACE programme developed the work stream 'Improving NHS cancer screening for people with a learning disability', aiming to: Reduce the inequality for PWLD in accessing the offers and processes; Increase uptake and Embed sustainable reasonable adjustments into services.

The work has developed a number of projects focusing locally, regionally and nationally making significant progress in reducing the inequality.

The bowel screening flagging project is a part of this broader piece of work aiming to offer support to PWLD through the active use of flagging. This enables support structures to be put in place throughout the screening process.

1.1 The bowel screening flagging project

To develop the bowel screening flagging project the North East and Cumbria Learning Disability Network worked in collaboration with; the local bowel screening hub, Clinical Commissioning Group (CCG), GP practices, community learning disability team (CLDT) and Cancer Research UK primary care facilitator.

The project was initially tested in South Tyneside Clinical Commissioning Group (CCG) area. This consists of 28 GP practices and is covered by; one bowel cancer screening hub, one bowel cancer screening centre and one CLDT.

The project developed a pathway that; identified, flagged and offered support to PWLD prior to point of invite to bowel cancer screening using the faecal occult blood test (FOBt). This enabled individually tailored work to support PWLD in making a choice about participation and being supported through the screening process.

The National Bowel Cancer Screening Programme made a change to the bowel cancer screening computer system (BCSS) in February 2016, this change enabled the flagging of individuals with an additional care need. Then in May 2016 it became possible to identify individuals with an additional care need note (such as a learning disability) through a search of the computer system, prior to an initial invitation being sent. This change in the computer system enabled the project test the use of this system change through the flagging project. We started the project on 9th May 2016 and this report discusses our results up to the 1st November 2016.

2.0 Method

The project worked in partnership to identify and test a system of flagging and support for PWLD invited for bowel cancer screening using the faecal occult blood test (FOBt). The process we devised is discussed below. The project aimed to test the process and adjust before offering to other CCG areas covered by the North East and Cumbria Network and North East Bowel Screening hub.

2.1 The process

The full process is described below in text and through the diagram on the next page.

An initial introduction letter regarding the project was sent to all GP practices by the GP cancer lead for the CCG, this introduced the project and its pathway. The letter also discussed the need to gain consent to share information with other health professionals through the enhanced learning disability annual health check.

The hub then contacted each GP practice requesting information regarding individuals with a learning disability, who had consented to have information shared, age 53 plus. The age of 53 was chosen as this is the age information is collated onto the bowel screening system, and it is anticipated that in the future the early identification of individuals being invited for bowel scope screening (at age 55) can be added to the project.

As information was received, from the GP practises by the hub, it was uploaded onto the system as an additional care needs note by a designated team leader. The Team Leader then ran a report using the bowel cancer screening system once a month to identify individuals who would be invited for screening in the following 4 weeks.

Once a PWLD was identified the team leaders contacted the CLDT with the individual’s details and the estimated arrival date of their invitation.

The CLDT then made an assessment of the level of support needed and offered tailored support to individuals. This could include but is not limited to; providing easy read information, providing one to one discussion, support in completing the FOBt, support attending appointments, support making best interest decision.

2.2 Information share pathway, for people with learning disabilities, invited for bowel cancer screening

GP practice to ensure learning disability lists are up to date.
Local community learning disability team can help with the checking of lists.

GP practice to gain consent to share information through the annual learning disability health check.
At annual health check for people with a learning disability ensure the individual has been asked if they are happy to have information shared to support their health and record answer.

Annual information request from the NHS bowel cancer screening programme (BCSP) hub

Information request for year one will be for all individuals that consented to information sharing aged **53-74.**
Information request in subsequent years will be all individuals that consented to information share aged **53-55**, have registered with the practice in the last year or aged 53-74 and have changed consent to share information.
Information to include Name, NHS no., DOB, address, reasonable adjustments required (if known)
Information to be shared with the hub on the provided excel spread sheet and returned via nhs.net

BCSP hub

BCSP software populated with names, DOB & address from age 53 of general population.
Hub to complete manual upload of learning disability information provided by GP practice into the additional care needs notes.

BCSP hub

4 weeks prior to pre invite letter the hub to complete a search of all individuals with additional care needs notes. Hub to action notes.

For individuals identified on the hub system as having a learning disability in the additional care needs notes and requiring additional support contact will be made with the relevant community learning disability team.

Hub to inform CLDT of the pre invitation.

CLDT receives information on pre invite approximately 2 weeks prior to pre invite being sent

CLDT to assess if person with a learning disability requires additional support.
For individuals that need additional support to understand / complete screening the CLDT offers support.

3.1 Results

The results are divided into three sections.

1. Quantitative data collated on the numbers of PWLD identified and supported.
2. Workload data collected by the main organisations involved in the delivery of work and estimating time spent on tasks.
3. Case studies

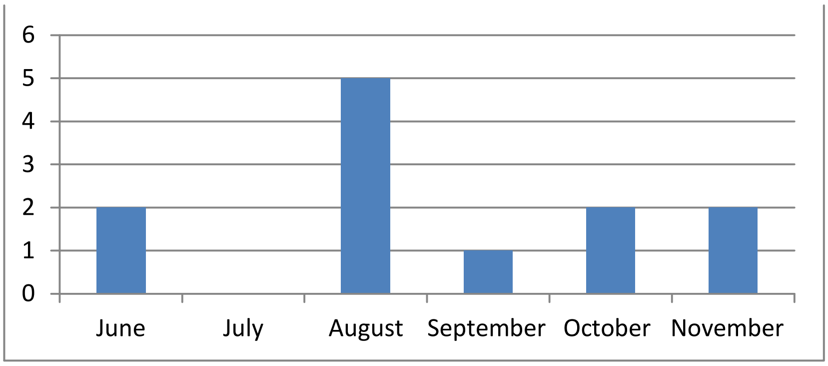
3.1 Quantitative data

Of the 28 GP practices, at time of writing, all have returned information to the bowel cancer screening hub regarding PWLD who have consented to share information aged 53 – 74.

Prior to the project 7 PWLD were known to the bowel cancer screening hub. They have now 209 PWLD flagged on their system as having a learning disability under the additional care needs note.

The hub have identified and passed information on 12 PWLD to the CLDT for additional support.

Number of PWLD who were identified by the hub and information shared with the CLDT, by month of invite



Of those PWLD notified to the CLDT the following outcomes are recorded. (Note; at time of writing a number of the individuals screening episodes are still open with results not yet inputted.)

- 3 individuals normal result, episode closed
- 1 individual, weak positive, awaiting additional test kit to be returned
- 3 individuals not yet responded, standard reminder letter sent
- 1 individual received abnormal result, later ceased due to unsuitability for diagnostic test, GP informed.
- 2 recent invites, no results currently recieved
- 2 about to be invited

3.2 Workload – hub

The work relating to the project in the hub is currently being completed by a team leader. It is anticipated all future work; communicating with GP's, inputting additional care needs notes and sharing information with the CLDT will be completed by a team leader, band 4 or above.

This information relates to the work completed within South Tyneside with the 28 GP practices.

In total it has taken approx. 6 hours to add the 209 individuals, identified by GP practices as having a learning disability and being within the age criteria in the South Tyneside CCG area, onto the bowel cancer screening system (BCSS) as an additional care needs note.

An average of, 2 minutes per individual.

Its takes on average, 13 minutes per practice, to add individuals onto the BCSS.

It takes approx. 8 minutes per referral to the community learning disability team per individual – total time taken so far 1 hour 18 mins for 12 referrals.

3.3 Workload – Community Learning Disability Team

Upon identification of an individual about to be invited for FOBt screening the community learning disability team allocated the individual to a health care support worker. For the PWLD identified to date this workload has averaged out at 3 visits to the client of approximately 30 minutes each, plus travel time.

When an individual is not previously known to the CLDT they approach sensitively and offer a needs assessment that could lead to further support being offered.

Individuals are kept on the case load of the health care support worker until they have chosen to not participate or they have participated and the screening round is completed.

3.4 Case Studies

The two case studies below describe the involvement of the community learning disability team in supporting PWLD to make choices on screening. Without the flagging project these individuals would have not been identified as about to be invited and would not have received support. Their names have been changed.

Moira

The Health Care Support Worker (HCSW) visited Moira, who has a learning disability, at her home. The HCSW explained the advantages of having bowel cancer screening; being able to pick up early signs that may be cancer which is easier to treat if identified in the early stages. Moira clearly looked really pleased saying her father had already being treated for bowel cancer and wanted to take part in this herself, she was eager to get started. The pack was sent to her home and the HCSW supported completion.

Jack

Jack received his bowel screening test kit and was offered support through a phone call. Jack decided to complete the kit himself. He completed the kit and sent it away. Jack received a letter asking him to repeat the test as it was incomplete; no dates were put on the test card. He decided he would complete another test kit, Jack completed the test kit and sent it away, unfortunately this was again not dated and Jack had put too much sample on the card. When he received a request for a further test kit to be completed he refused and put the test kit in the bin. Jack told the HCSW he had not received it and would not complete any more. HCSW visited Jack who was adamant he was not completing the screening again. After a discussion with the HCSW about the benefits, using easy read leaflets he reluctantly said he would complete another set of samples, the screening was completed with the HCSW support and the results came back fine, the kit did not need to be repeated. Jack was very pleased he had accepted the support from CLDT and thanked the HCSW involved.

4.0 Discussion and comments

The discussion and comments have been divided into a number of sub sections to describe some of the thinking and issues that arose as part of this project.

4.1 Consent to share information

When you are supporting individuals and sharing their information between services there are always questions around consent to be answered. We all have a right to our information remaining private. The screening programmes are not identified as direct patient care therefor consent is needed before personal information can be shared with screening services.

The enhanced learning disability annual health check is the ideal opportunity to identify with a PWLD if they are happy for information to be shared with screening services and start discussions about screening.

Where an individual lacks the capacity to consent a best interest decision would need to be made regarding the sharing of information.

When we look to roll out this work into other CCG areas we will be clearly stating in all communication the need to gain consent to share information.

4.2 Sign up by GP Practices

South Tyneside CCG and the Cancer Research UK Primary Care Facilitator supported the sign up of GP practices through discussing the project whilst doing practice visits.

Not all GP practices shared information immediately, but all had signed up and shared information by October 2016.

It is worth noting this project has not been part of an enhanced payment scheme for GP's and the additional work has been completed as best practice for their patients with a learning disability.

4.3 Training Community Learning Disability Team

Prior to the project the South of Tyne Bowel Cancer Screening Centre completed a training session for the CLDT. This ensured the team understood the process of screening and choice for the individual being invited.

CLDT members also attended a number of training events held by the North East and Cumbria Learning Disability Network including; primary care training and the Good Bowel Health and Bowel Screening train the trainers course.

It will be expected that all new CLDT's coming on board with the project will receive training from the bowel cancer screening centre to ensure their knowledge base and make links with the screening centre staff.

5.0 Conclusion and moving forward

We have a legal responsibility through the Equalities Act to provide reasonable adjustments for people with learning disabilities, to make changes in our approach/provision to ensure that services are accessible to disabled people as well as everybody else.

The bowel screening flagging project has tested and evaluated a process that can be replicated to improve the invitation process and support structures for PWLD.

Following this trial period it is anticipated the project will look to roll out into other CCG areas and look to share its learning to enable other areas to develop similar work.

This work shows the benefits of flagging in enabling support for PWLD and should feed into the wider work on reducing the inequalities faced by PWLD trying to access services.

References

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[i] 2. Emerson E, Baines S, Allerton L and Welch V. (2012) Health inequalities and People with Learning Disabilities in the UK:2012. Improving Health and Lives Learning Disabilities Public Health Observatory http://www.ihal.org.uk/gsf.php5?f=16453 (accessed 03/11/2016)

[ii] Heslop P, Blair P, Fleming P, Hoghton M, Marriott A and Russ L. (2013) Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final report. Bristol: Norah Fry Research Centre, University of Bristol http://www.bristol.ac.uk/cipold/reports/ (accessed 15th 03/11/2016)

[iii] Connolly J. (2013) Barriers to access to cancer screening for people with learning disabilities: a review. The Lancet; 382(3): S29

[iv] Heslop P, Blair P, Fleming P, Hoghton M, Marriott A and Russ L. (2013) Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final report. Bristol: Norah Fry Research Centre, University of Bristol http://www.bristol.ac.uk/cipold/reports/ (accessed 15th 03/11/2016)

The Electronic Health Equality Framework

Ashley Murphy

Measuring the outcomes of effective services

What is it?

- Evidence based outcomes framework
- Systematically developed
- Measures the contribution of services in reducing exposure to known determinants of health inequality

The Challenge of Demonstrating Outcomes in Learning Disabilities

- Wide variations in service models & structures
- Varied / changing commissioning structures / priorities
- No authoritative comparative national dataset relating to the health of people with learning disabilities as a discrete population.
- Lack of gold standards (no valid outcome measures)
- Little nursing research on outcomes in LD

What it can tell us?

- It can tell us when unmet need is evident
- It can tell us what we are doing well and areas that need to improve.
- It can help us formulate a care pathway.
- It can help us articulate that someone is ready for discharge.
- It can help us identify social issues and enable us to articulate to social care colleagues.
- It can facilitate conversation and planning with other care providers.

Point of Use

- For community teams profile at point of referral and discharge.
- HEF scores at the point of referral may provide a basis for triage assessment processes.
- Within community teams, HEF scores may form part of a caseload weighting process in order to inform allocations.
- HEF scores may be reviewed during CPA meetings, Health Action Plan reviews, Person Centred reviews etc.
- Within long term forms of service provision e.g. residential care homes or supported accommodation, routine HEF scoring may be useful at regular intervals e.g. every three months.
- HEF scoring prior to and post hospital stays is useful in establishing whether valid outcomes have been achieved.

Point of Use

- For practitioners who carry a caseload, HEF monitoring can inform prioritisation.
- Reviewing HEF profiles before and after interventions can inform an understanding of their effectiveness
- Individual caseload data can be aggregated and analysed.
- For managers of services, the ability to aggregate outcomes data across teams & practitioners can inform performance management.
- For strategic service planners the ability to correlate HEF profiles against biographical details and specific profiles of service user need allows service improvements to be planned around local population profiles.
- Professional groups can use the profile to demonstrate the value of their contribution.

Lessons from implementing the HEF

The following general points have been made regarding implementation:

- It is important to ensure that there is a good understanding of what the HEF is measuring – the exposure to the determinants of health inequalities – not what individual clinicians are doing
- The HEF does not replace other tools the team might be using for specific issues regarding things like mental health problems and pain assessments.

Lessons from implementing the HEF

- There are risks to comparing scores from different services working in different ways with different people
- Helpful to flag the HEF during the new CQC inspection visits
- The underpinning evidence document is helpful for supervision and to use with students, but is not something that should be used routinely for all

Lessons from implementing the HEF

- HEF scores prompt further questions about what is going on – for example issues regarding where a person lives

- Aggregated HEF data should prompt further questions to understand what is happening rather than leaping to conclusions about service or support deficits
- It would be helpful to share HEF data with local Health and Wellbeing Boards
- It is helpful to add a pdf copy of the HEF profile to the care record or discharge plan

What we did

- Completed a pilot over 6 month period.
- Opened a shared folder where EHEF info was stored.
- Focused on 10 clients with physical health issues in the main both in Newcastle and Sunderland.
- Each assessment took 30 mins.
- Identified a baseline EHEF score.
- Repeated it in 3 months time with good outcomes.
- Shared with Trust quality group who agreed further assessments should take place to include PBS and mental health.

5 Determinants of Health Inequalities

- Social
- Genetic & Biological
- Behavioural
- Communication & Health literacy
- Service access / quality

Health Inequality Indicators

1. Social

A. Accommodation
B. Employment & meaningful activities
C. Financial support
D. Social contact
E. Additional marginalising factors (such as ethnicity)
F. Safeguarding issues

2. Genetic and Biological

A. Assessment of physical & mental health needs and health checks
B. Long Term Condition pathways & planned reviews of need
C. Care Planning & Health Action Planning
D. Crisis / emergency planning & hospital passports
E. Medication
F. Specialist service provision

3. Communication

A. Poor bodily awareness & reduced pain responses
B. Difficulty communicating health needs to others
C. Carers failure to recognise pain / distress
D. Carers ability to recognise and respond to emerging health problems and / or promote health literacy
E. Understanding health information & making choices

4. Behaviour & Lifestyle

A. Diet
B. Exercise
C. Weight
D. Substance use
E. Sexual Health
F. Risky Behaviours / routines

5. Service Quality

A. Organisational barriers
B. Consent
C. Transitions
D. Health screening / promotion
E. Primary Secondary services
F. Non health services

Impact Ratings

Impact Rating	Likely consequences if not addressed
4 = Major	Health problems are associated with premature death. There may be multiple permanent injuries or irreversible significant long term health effects. Significant and prolonged restriction of normal activities and high risk of unplanned hospital admissions.
3 = Significant	Major injuries and periods of ill health are likely, leading to long-term incapacity/disability and potential premature death. There may be prolonged periods of inability to engage in usual routines. May require complex and prolonged treatment. Likely to have recurrent unplanned hospital admissions.
2 = Limited	Prone to moderate injury / illness requiring skilled professional intervention. Typified by recurrent breaks in engagement with normal routines. Recovery period following injury / illness several weeks longer than usual. Therapeutic intervention has significantly reduced in (?) effectiveness
1 = Minimal	The person is likely to suffer minor injuries or illnesses which are likely to require minor intervention. There may be some intermittent short lived (i.e. a few days) impairment of engagement in usual activities. Recovery from periods of ill health may be slightly slower than would otherwise be the case.
0 = No impact	Minimal impact requiring no/minimal intervention or treatment .

A. Accommodation

The quality of living standards for people with learning disabilities can vary widely. When considering accommodation it is important to consider the physical and the social environment. Risks may exist because of the physical environment (extreme damp, unsafe electrics, lack of adaptation around mobility problems etc.), or arise from the social environment (overcrowding, bullying, aggression from others, etc).

Impact Level & Indicator Statement		**Descriptor**
4A	Accommodation presenting high risk, or in hospital / prison with no discharge accommodation identified or homeless.	*This level applies to a person who has no settled accommodation, who may be in temporary short term accommodation with no appropriate move-on accommodation identified, or in accommodation that is directly impacting on their health and wellbeing. This includes those who are living in restrictive settings such as hospitals or prison. There may be serious safeguarding concerns in relation to accommodation.*
3A	Inappropriate accommodation / accommodation at risk of breakdown.	*This level applies where a person is in accommodation which is does not meet to their identified health and social needs; or where the accommodation is fragile and likely to break down (e.g. due to negative relationships with peers / neighbours, lack of suitably skilled support, offending behaviour, or where notice has been served by the accommodation provider).*
2A	Shared accommodation with others / family – not by choice.	*This level applies where accommodation is shared with others though not either chosen by the individual, or agreed through an appropriate best interest process. Similarly, where individuals continue to live with their family despite the fact that they or their family would prefer independence move to more independent living.*
1A	Settled single accommodation or shared with self-selected others.	*This level applies where a person lives in accommodation either of their choosing or following appropriate best interest processes. This will however be in some form of registered care or where they do not have tenancy rights or full control over their care and / or support.*
0A	Settled family accommodation or own tenancy / ownership reflecting personal choice.	*This level applies where a person is in settled accommodation either of their choosing or following a appropriate best interest process. Either the person themselves of their family have control over their tenancy, care and support.*

A case study : 'Ray'

- Ray is a 64 years old and has moderate learning disabilities
- He was referred to the community nurse because he was thought to be losing weight
- On assessment the nurse found Ray had not seen a doctor for some years
- He had become withdrawn, non-communicative and reclusive not wanting to go out and generally unhappy

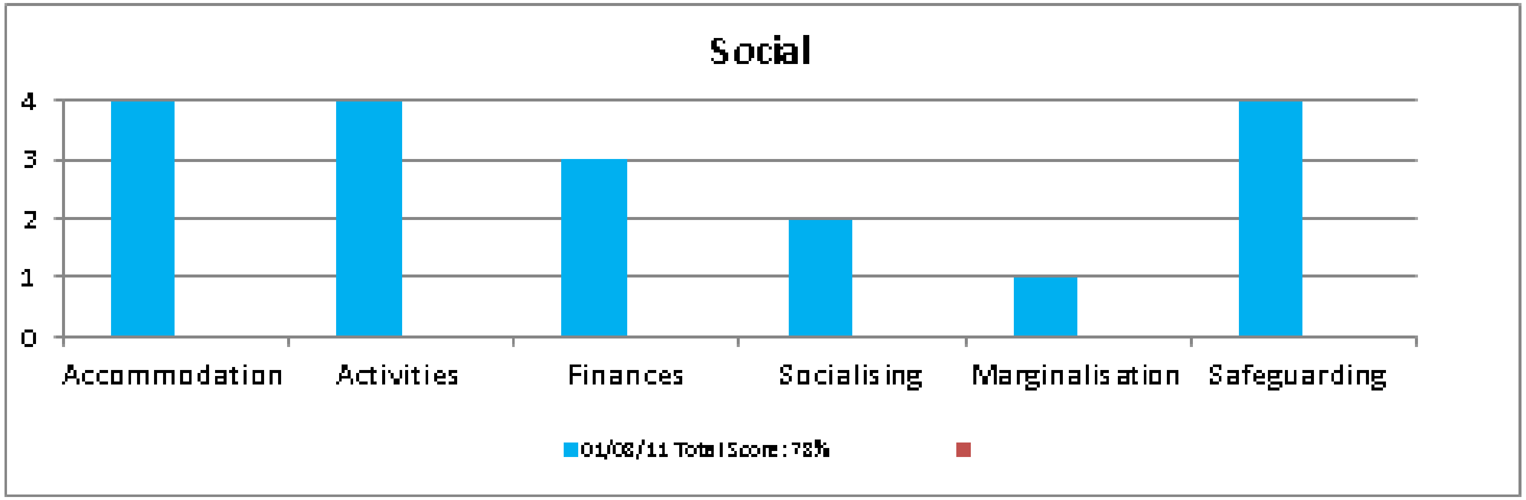
A case study : 'Ray'

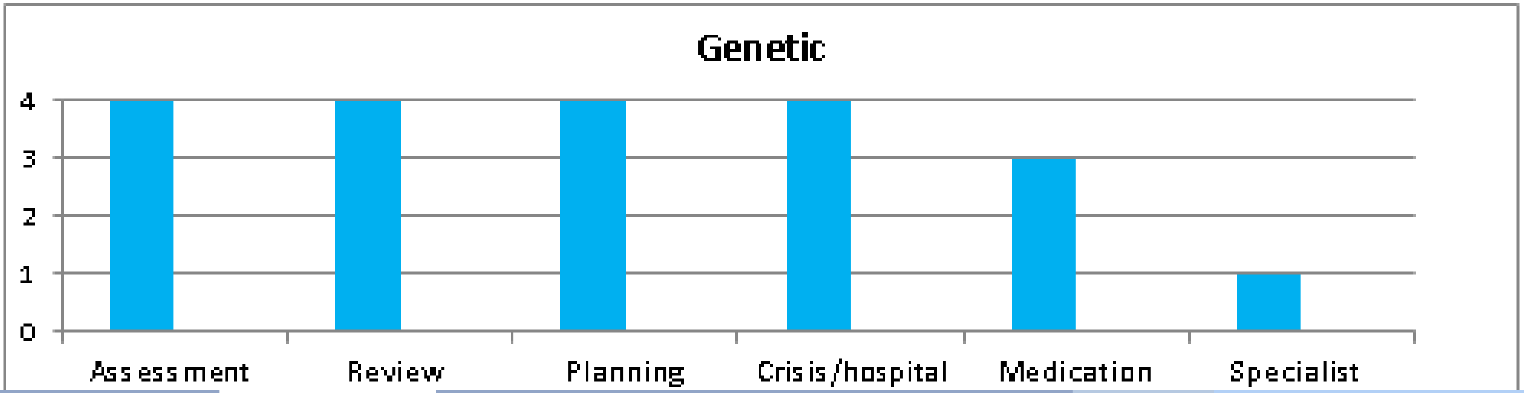
- Ray had become verbally abusive towards the staff who provided his care and support
- Ray's staff thought he was being awkward and wanted help to manage his behaviour
- Following initial assessment the nurse was concerned there may be some serious health problems and arranged for him to see his doctor for a full health check

A case study : ‘Ray’

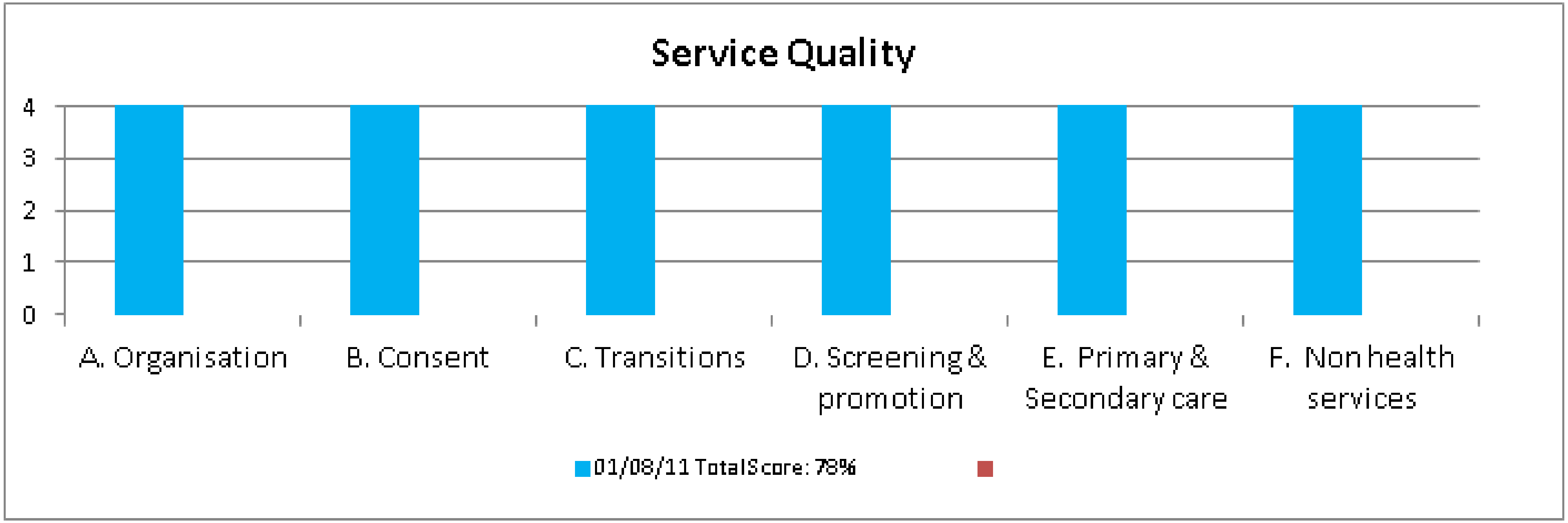
- Following a number of health tests Ray was found to have terminal prostate cancer
- He was receiving no treatment or pain relief and was socially isolated and miserable
- Ray has no known family and had lost contact with friends

Ray’s eHEF initial score – August 2011

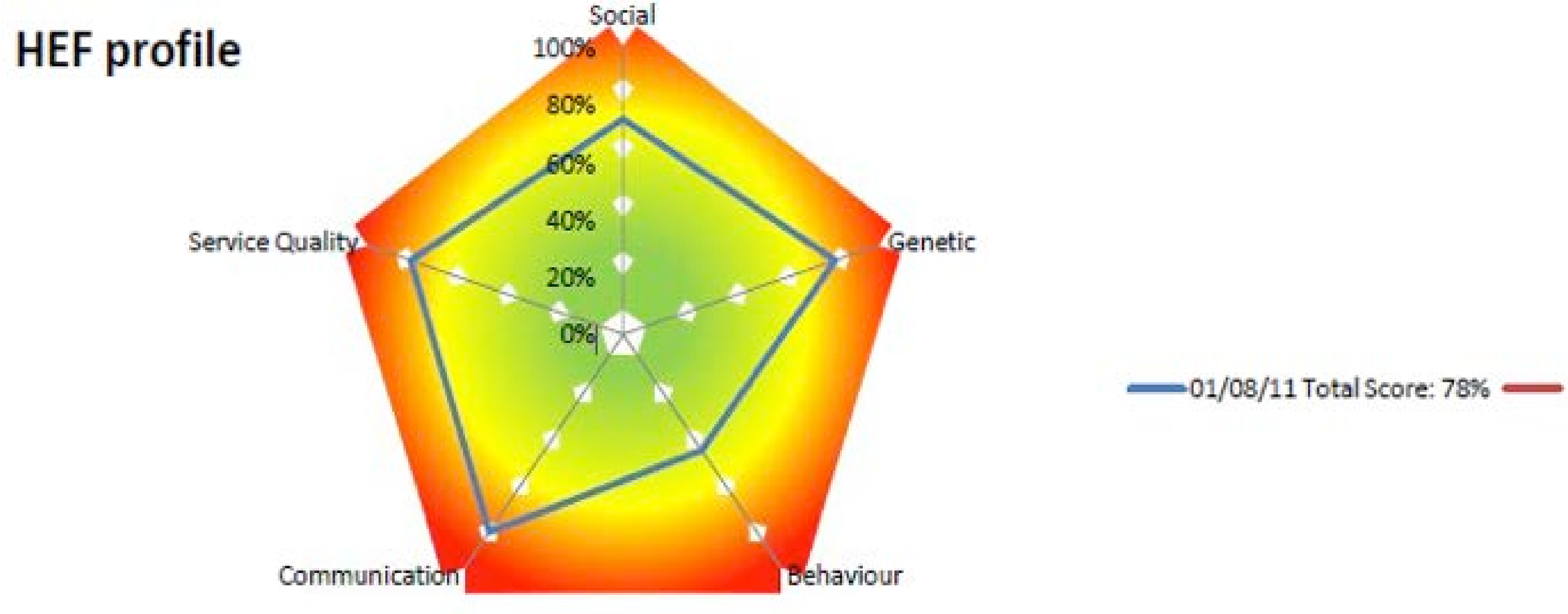




Ray’s eHEF initial score – August 2011



Ray’s initial Health Inequalities score – August 2011 : 78%



Interventions : What did the nurse do?

- Supported Ray to have a full health check
- Worked with GP and other health staff to help them make reasonable adjustments so they could fully assess, diagnose and treat Ray
- Completed a pain picture to help hospital and support staff know when Ray is in pain

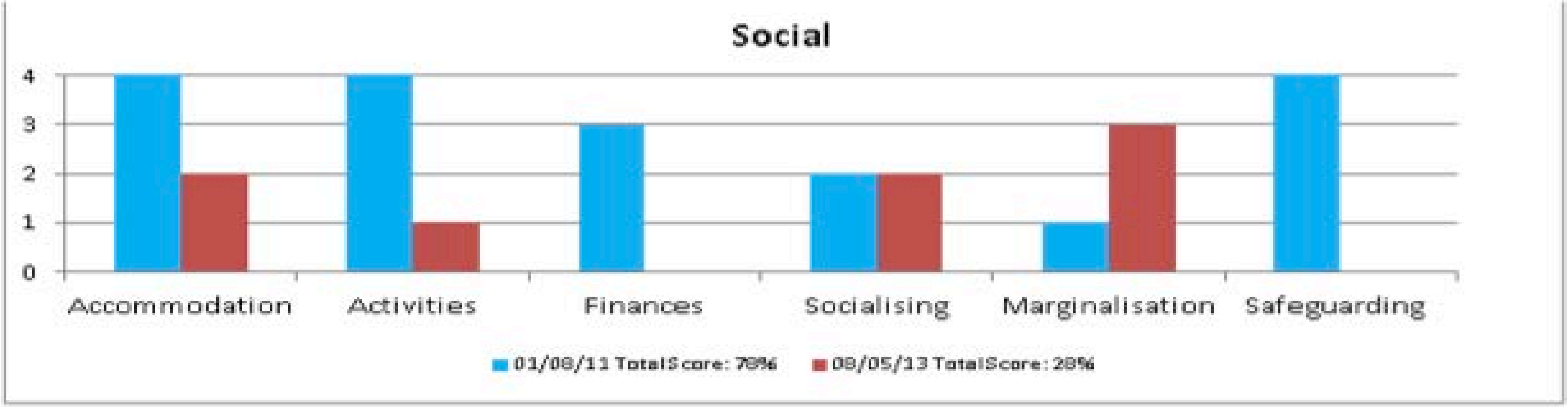
Interventions : What did the nurse do?

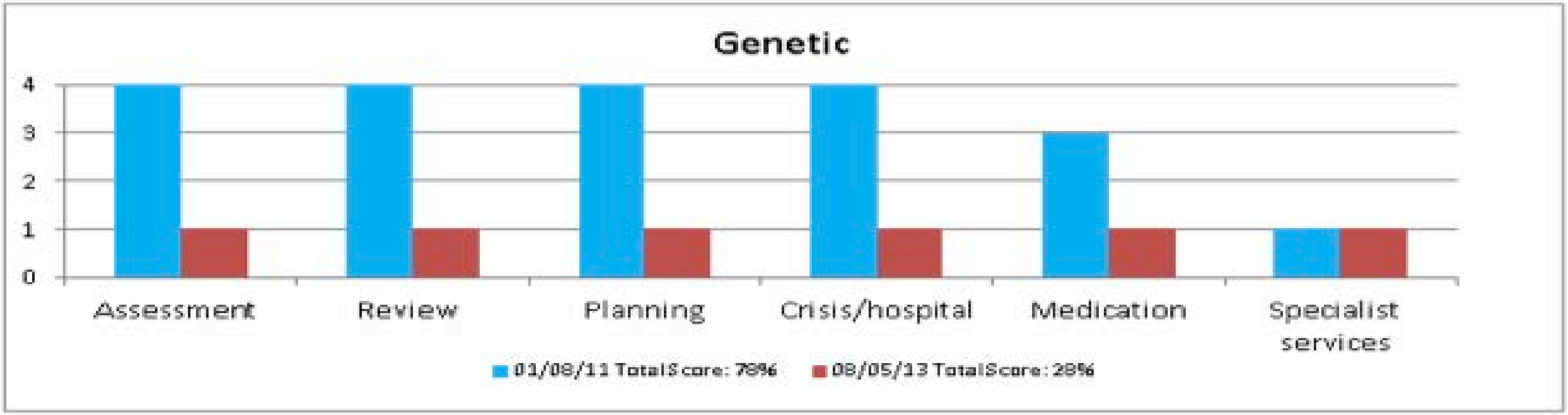
- Worked with social worker and continuing health care nurse to enable Ray to move to a nursing home where he gets the right care and support
- Taught staff in the nursing home how to communicate with Ray effectively and care for his specific needs related to his learning disability

Interventions : What did the nurse do?

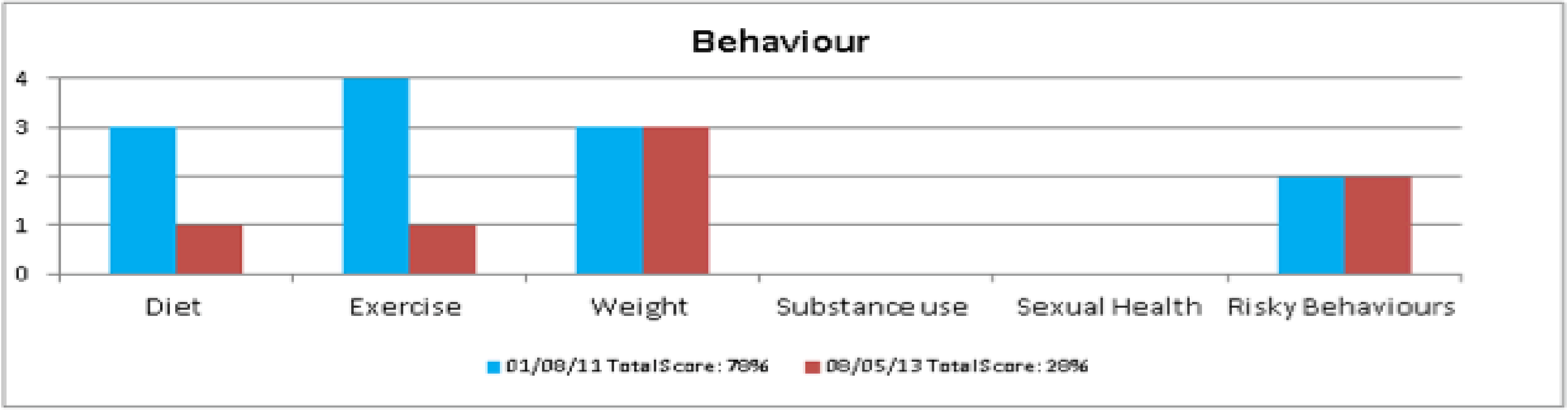
- Worked with a health care support worker to build a history of Ray’s life identifying the things that are important to him from his past
- Worked with the support worker to help Ray reconnect with old friends and enable a more varied lifestyle including activities like going out when he is well enough
- Worked with palliative care staff to create a person centred end of life plan

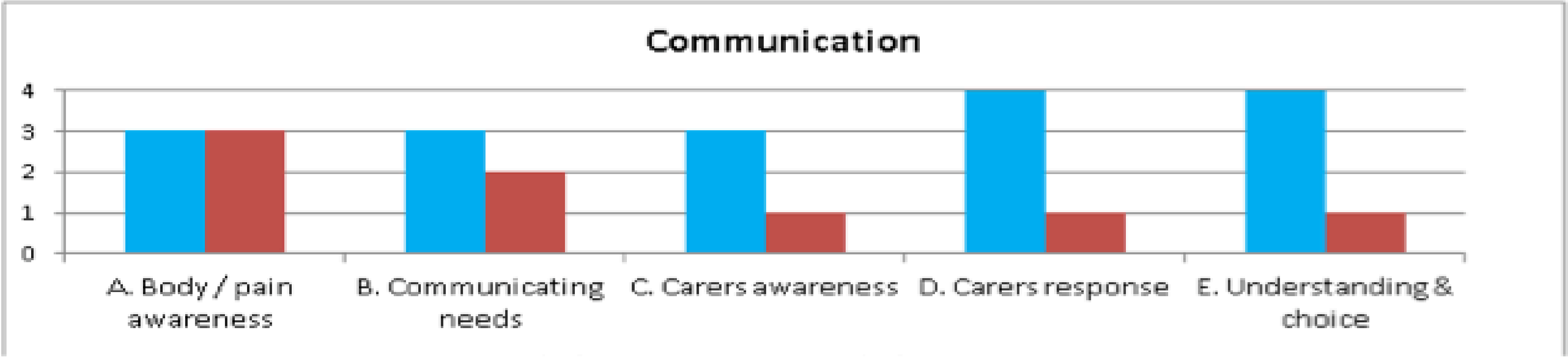
Ray's eHEF Score : June 2013



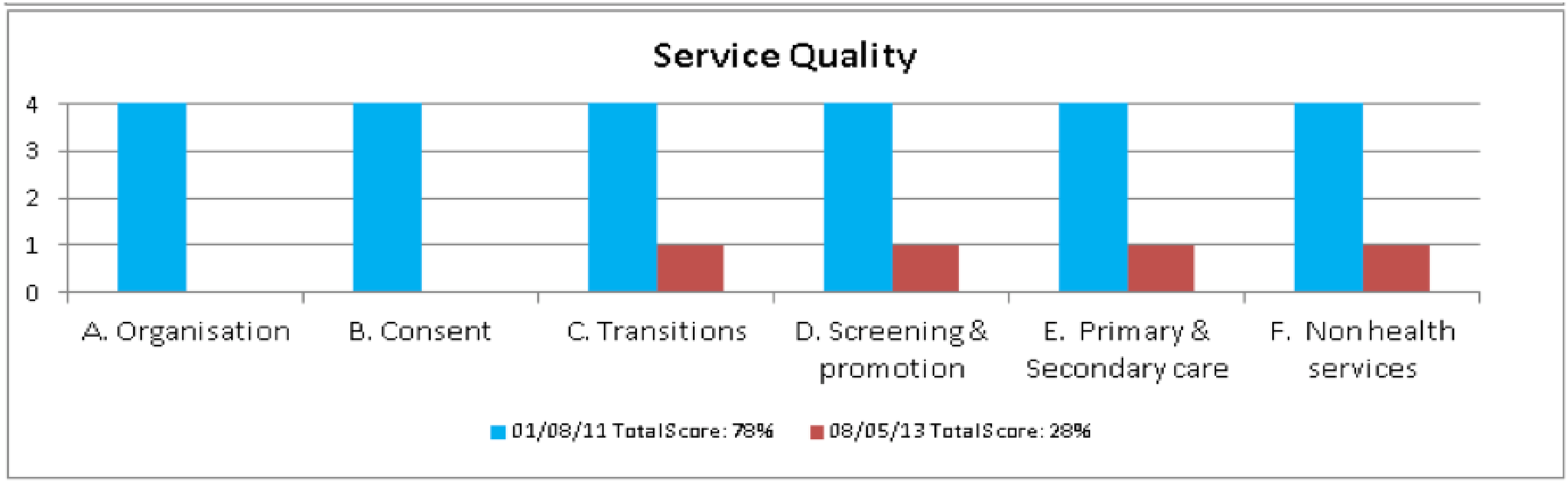


Ray’s eHEF Score : June 2013

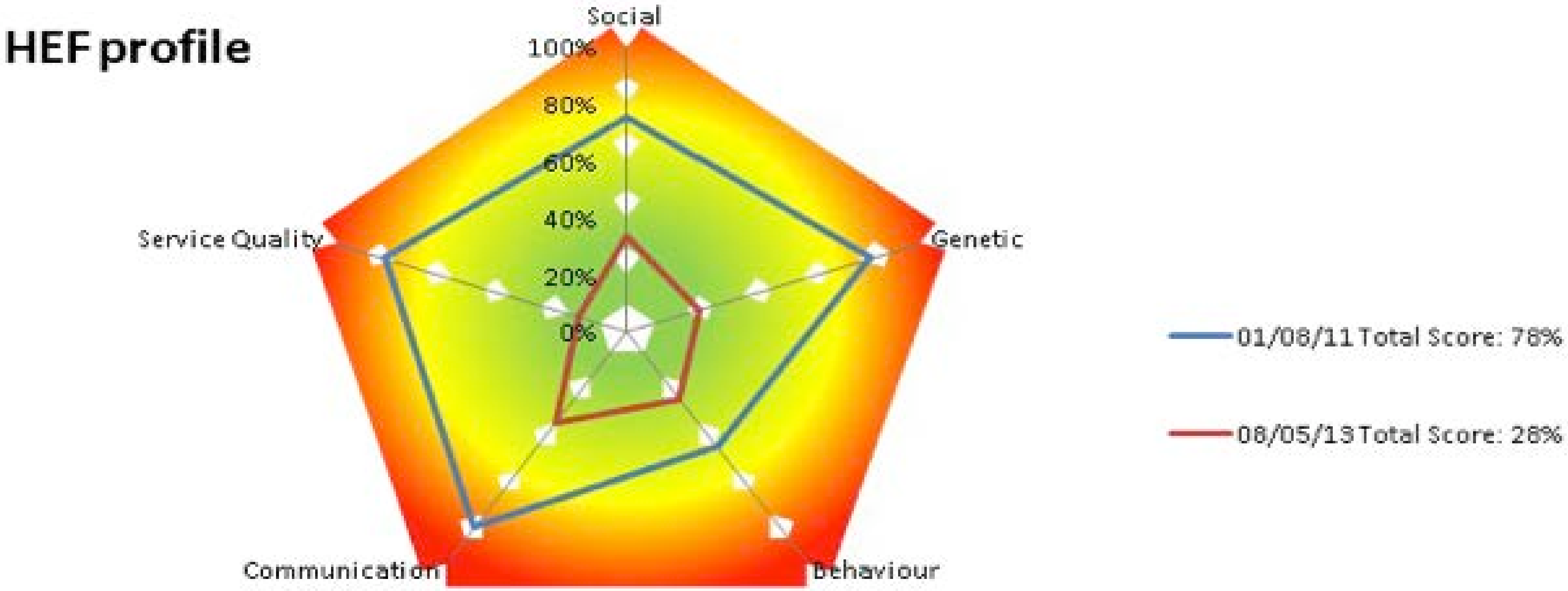




Ray’s eHEF Score : June 2013



Ray's health inequalities score after interventions June 2013 : 28%



What Next?

Carry out further assessments in PBS and mental health for a baseline EHEF score.

Repeat after a 3 month duration.

Provide findings to trust board for their steer on rolling it out across the team.

Provide training on the EHEF tools.

Wait for more info on roll out due to CQUIN.

NICE National Institute for Health and Care Excellence

NICE guideline

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges

NICE guideline
Published: 29 May 2015
nice.org.uk/guidance/ng11

Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The application of the recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Local commissioners and/or providers have a responsibility to enable the guideline to be applied when individual health professionals and their patients or service users wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with compliance with those duties.

Contents

This guideline is the basis of QS101 and QS142.

Overview

This guideline covers interventions and support for children, young people and adults with a learning disability and behaviour that challenges, and ways of preventing challenging behaviour. It aims to improve quality of life as well as red. The guideline also covers support and intervention for family members or carers.

NICE has produced an easy read version for people with a learning disability.

Who is it for?

- Healthcare professionals, commissioners and providers in health and social care
- Parents, family members or carers of children, young people and adults with a learning disability and behaviour that challenges

Introduction

A learning disability is defined by 3 core criteria: lower intellectual ability (usually an IQ of less than 70), significant impairment of social or adaptive functioning, and onset in childhood. Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability. Although the term 'intellectual disability' is becoming accepted internationally, 'learning disability' is the most widely used and accepted term in the UK and is therefore used in this guideline. The amount of everyday support a person with a learning disability needs will depend mostly on the severity of the disability. It is important to treat each person as an individual, with specific strengths and abilities as well as needs, and a broad and detailed assessment may be needed.

Some people with a learning disability display behaviour that challenges. 'Behaviour that challenges' is not a diagnosis and is used in this guideline to indicate that although such behaviour is a challenge to services, family members or carers, it may serve a purpose for the person with a learning disability (for example, by producing sensory stimulation, attracting attention, avoiding demands and communicating with other people). This behaviour often results from the interaction between personal and environmental factors and includes aggression, self-injury, stereotypic behaviour, withdrawal, and disruptive or destructive behaviour. It can also include violence, arson or sexual abuse, and may bring the person into contact with the criminal justice system.

It is relatively common for people with a learning disability to develop behaviour that challenges, and more common for people with more severe disability. Prevalence rates are around 5–15% in educational, health or social care services for people with a learning disability. Rates are higher in teenagers and people in their early 20s, and in particular settings (for example, 30–40% in hospital settings). People with a learning disability who also have communication difficulties, autism, sensory impairments, sensory processing difficulties and physical or mental health problems (including dementia) may be more likely to develop behaviour that challenges.

The behaviour may appear in only certain environments, and the same behaviour may be considered challenging in some settings or cultures but not in others. It may be used by the person for reasons such as creating sensory stimulation, getting help or avoiding demands. Some care environments increase the likelihood of behaviour that challenges. This includes those with limited opportunities for social interaction and meaningful occupation, lack of choice and sensory input or excessive noise. It also includes care environments that are crowded, unresponsive or unpredictable, those characterised by neglect and abuse, and those where physical health needs and pain go unrecognised or are not managed.

Multiple factors are likely to underlie behaviour that challenges. To identify these, thorough assessments of the person, their environment and any biological predisposition are needed, together with a functional assessment. Interventions depend on the specific triggers for each person and may need to be delivered at multiple levels (including the environmental level). The aim should always be to improve the person's overall quality of life.

This guideline will cover the care and shared care provided or commissioned by health and social care, in whatever care setting the person lives.

Safeguarding children

Remember that child maltreatment:

- is common
- can present anywhere, such as emergency departments and primary care or on home visits.

Be aware of or suspect abuse as a contributory factor to or cause of behaviour that challenges shown by children with a learning disability. Abuse may also coexist with behaviour that challenges. See the NICE guideline on child maltreatment for clinical features that may be associated with maltreatment.

This section has been agreed with the Royal College of Paediatrics and Child Health.

Safeguarding adults

Adults with a learning disability are vulnerable to maltreatment and exploitation. This can occur in both community and residential settings. A referral (in line with local safeguarding procedures) may be needed if there are concerns regarding maltreatment or exploitation, or if the person is in contact with the criminal justice system.

Medication

The guideline will assume that prescribers will use a medication's summary of product characteristics to inform decisions made with people offered medication (or their family members or carers, as appropriate).

This guideline recommends some medications for indications for which they do not have a UK marketing authorisation at the date of publication, if there is good evidence to support that use.

The prescriber should follow relevant professional guidance, taking full responsibility for the decision. The person offered the medication (or those with authority to give consent on their behalf) should provide informed consent, which should be documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information. Where recommendations have been made for the use of medicines outside their licensed indications ('off-label use'), these medicines are marked with a footnote in the recommendations.

Person-centred care

This guideline offers best practice advice on the care of children, young people and adults with a learning disability and behaviour that challenges.

People who use health services and healthcare professionals have rights and responsibilities as set out in the NHS Constitution for England – all NICE guidance is written to reflect these. In addition, adults, carers and local authorities have rights and responsibilities set out in the Care Act 2014 (the majority of which took effect from April 2015). Treatment and care should take into account individual needs and preferences. People who use health and social care services should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals and social care practitioners. If the person is under 16, their family or carers should also be given information and support to help the child or young person to make decisions about their treatment. If it is clear that the child or young person fully understands the treatment and does not want their family or carers to be involved, they can give their own consent. Healthcare professionals should follow the Department of Health's advice on consent. If someone does not have capacity to make decisions, healthcare professionals should follow the code of practice that accompanies the Mental Capacity Act and the supplementary code of practice on deprivation of liberty safeguards.

NICE has produced guidance on the components of good patient experience in adult NHS services. All healthcare professionals should follow the recommendations in patient experience in adult NHS services.

NICE has also produced guidance on the components of good service user experience. All healthcare professionals and social care practitioners working with people using adult NHS mental health services should follow the recommendations in service user experience in adult mental health.

If a young person is moving between child and adult services, care should be planned and managed according to the best practice guidance described in the Department of Health's Transition: getting it right for young people.

Adult and child health and social care teams should work jointly to provide assessment and services to young people with a learning disability and behaviour that challenges. Diagnosis and management should be reviewed throughout the transition process, and there should be clarity about who is the lead clinician to ensure continuity of care.

Key priorities for implementation

The following recommendations have been identified as priorities for implementation. The full list of recommendations is in section 1.

General principles of care

Working with people with a learning disability and behaviour that challenges, and their families and carers

- When providing support and interventions for people with a learning disability and behaviour that challenges, and their family members or carers:
    - take into account the severity of the person's learning disability, their developmental stage, and any communication difficulties or physical or mental health problems
    - aim to provide support and interventions:
        - in the least restrictive setting, such as the person's home, or as close to their home as possible, and
        - in other places where the person regularly spends time (for example, school or residential care)
    - aim to prevent, reduce or stop the development of future episodes of behaviour that challenges
    - aim to improve quality of life
    - offer support and interventions respectfully
    - ensure that the focus is on improving the person's support and increasing their skills rather than changing the person
    - ensure that they know who to contact if they are concerned about care or interventions, including the right to a second opinion
    - offer independent advocacy to the person and to their family members or carers.

Delivering effective care

- If initial assessment (see section 1.5) and management have not been effective, or the person has more complex needs, health and social care provider organisations should ensure that teams providing care have prompt and coordinated access to specialist assessment, support and intervention services. These services should provide advice, supervision and training from a range of staff to support the implementation of any care or intervention, including psychologists, psychiatrists, behavioural analysts, nurses, social care staff, speech and language therapists, educational staff, occupational therapists, physiotherapists, physicians, paediatricians and pharmacists.

Support and interventions for family members or carers

- When providing support to family members or carers (including siblings):
  - recognise the impact of living with or caring for a person with a learning disability and behaviour that challenges
  - explain how to access family advocacy
  - consider family support and information groups if there is a risk of behaviour that challenges, or it is emerging
  - consider formal support through disability-specific support groups for family members or carers and regular assessment of the extent and severity of the behaviour that challenges
  - provide skills training and emotional support, or information about these, to help them take part in and support interventions for the person with a learning disability and behaviour that challenges.

Early identification of the emergence of behaviour that challenges

- Everyone involved in caring for and supporting children, young people and adults with a learning disability (including family members and carers) should understand the risk of behaviour that challenges and that it often develops gradually. Pay attention to and record factors that may increase this risk, including:
  - personal factors, such as:
    - a severe learning disability

    - autism
    - dementia
    - communication difficulties (expressive and receptive)
    - visual impairment (which may lead to increased self-injury and stereotypy)
    - physical health problems
    - variations with age (peaking in the teens and twenties)
  - environmental factors, such as:
    - abusive or restrictive social environments
    - environments with little or too much sensory stimulation and those with low engagement levels (for example, little interaction with staff)
    - developmentally inappropriate environments (for example, a curriculum that makes too many demands on a child or young person)
    - environments where disrespectful social relationships and poor communication are typical or where staff do not have the capacity or resources to respond to people's needs
    - changes to the person's environment (for example, significant staff changes or moving to a new care setting).

Assessment of behaviour that challenges

The assessment process

- When assessing behaviour that challenges ensure that:
  - the person being assessed remains at the centre of concern and is supported throughout the process
  - the person and their family members and carers are fully involved in the assessment process
  - the complexity and duration of the assessment process is proportionate to the severity, impact, frequency and duration of the behaviour

  - everyone involved in delivering assessments understands the criteria for moving to more complex and intensive assessment (see recommendation 1.5.8)
  - all current and past personal and environmental factors (including care and educational settings) that may lead to behaviour that challenges are taken into account
  - assessment is a flexible and continuing (rather than a fixed) process, because factors that trigger and maintain behaviour may change over time
  - assessments are reviewed after any significant change in behaviour
  - assessments are focused on the outcomes of reducing behaviour that challenges and improving quality of life
  - the resilience, resources and skills of family members and carers are taken into account
  - the capacity, sustainability and commitment of the staff delivering the behaviour support plan (see recommendation 1.6.1) are taken into account.

Risk assessment

- Assess and regularly review the following areas of risk during any assessment of behaviour that challenges:
  - suicidal ideation, self-harm (in particular in people with depression) and self-injury
  - harm to others
  - self-neglect
  - breakdown of family or residential support
  - exploitation, abuse or neglect by others
  - rapid escalation of the behaviour that challenges.

Ensure that the behaviour support plan includes risk management (see recommendation 1.6.1).

Functional assessment of behaviour

- Vary the complexity and intensity of the functional assessment according to the complexity and intensity of behaviour that challenges, following a phased approach as set out below.

  - Carry out pre-assessment data gathering to help shape the focus and level of the assessment.
  - For recent-onset behaviour that challenges, consider brief structured assessments such as the Functional Analysis Screening Tool or Motivation Assessment Scale to identify relationships between the behaviour and what triggers and reinforces it.
  - For recent-onset behaviour that challenges, or marked changes in patterns of existing behaviours, take into account whether any significant alterations to the person's environment and physical or psychological health are associated with the development or maintenance of the behaviour.
  - Consider in-depth assessment involving interviews with family members, carers and others, direct observations, structured record keeping, questionnaires and reviews of case records.
  - If a mental health problem may underlie behaviour that challenges, consider initial screening using assessment scales such as the Diagnostic Assessment Schedule for the Severely Handicapped-II, Psychiatric Assessment Schedule for Adults with a Developmental Disability or the Psychopathology Instrument for Mentally Retarded Adults and seek expert opinion.

Psychological and environmental interventions

Interventions for behaviour that challenges

- Consider personalised interventions for children, young people and adults that are based on behavioural principles and a functional assessment of behaviour, tailored to the range of settings in which they spend time, and consist of:
  - clear targeted behaviours with agreed outcomes
  - assessment and modification of environmental factors that could trigger or maintain the behaviour (for example, altering task demands for avoidant behaviours)
  - addressing staff and family member or carer responses to behaviour that challenges
  - a clear schedule of reinforcement of desired behaviour and the capacity to offer reinforcement promptly
  - a specified timescale to meet intervention goals (modifying intervention strategies that do not lead to change within a specified time).

Medication

- Consider antipsychotic medication to manage behaviour that challenges only if:
  - psychological or other interventions alone do not produce change within an agreed time or
  - treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour or
  - the risk to the person or others is very severe (for example, because of violence, aggression or self-injury).

Only offer antipsychotic medication in combination with psychological or other interventions.

1 Recommendations

The following guidance is based on the best available evidence. The full guideline gives details of the methods and the evidence used to develop the guidance.

> The wording used in the recommendations in this guideline (for example, words such as 'offer' and 'consider') denotes the certainty with which the recommendation is made (the strength of the recommendation). See about this guideline for details.

Children, young people and adults

This guideline covers people of all ages with a learning disability and behaviour that challenges. All recommendations relate to children, young people and adults unless specified otherwise. These terms are defined as follows:

- children: aged 12 years or younger
- young people: aged 13 to 17 years
- adults: aged 18 years or older.

Terms used in this guideline

Behavioural phenotypes

The expression of distinctive physiological and behavioural characteristics that have a chromosomal or genetic cause.

Carer

A person who provides unpaid support to a partner, family member, friend or neighbour who is ill, struggling or has a disability. This does not include paid carers (care workers), who are included in the definition of staff.

Expressive communication

The ability to express thoughts, feelings and needs verbally (using words and sentences) and non-verbally (for example, using gestures, facial expressions, gaze, signing and other methods that supplement or replace speech or writing).

Functional assessment

An assessment of the function of behaviour that challenges, including functional analyses and other methods of assessing behavioural functions.

Reactive strategies

Any strategy used to make a situation or a person safe when they behave in a way that challenges. This includes procedures for increasing personal space, disengagement from grabs and holds, p.r.n. (as-needed) medication and more restrictive interventions.

Receptive communication

The ability to understand or comprehend language (either spoken or written) or other means of communication (for example, through signing and other methods that supplement or replace speech or writing).

Reinforcer

An event or situation that is dependent on a behaviour and increases the likelihood of that behaviour happening again.

Restrictive interventions

Interventions that may infringe a person's human rights and freedom of movement, including locking doors, preventing a person from entering certain areas of the living space, seclusion, manual and mechanical restraint, rapid tranquillisation and long-term sedation.

Self-harm

When a person intentionally harms themselves, which can include cutting and self-poisoning. It may be an attempt at suicide.

Self-injury

Frequently repeated, self-inflicted behaviour, such as people hitting their head or biting themselves, which can lead to tissue damage. This behaviour is usually shown by people with a severe learning disability. It may indicate pain or distress, or it may have another purpose, such as the person using it to communicate.

Staff

Healthcare professionals and social care practitioners, including those working in community teams for adults or children (such as psychologists, psychiatrists, social workers, speech and language therapists, nurses, behavioural analysts, occupational therapists, physiotherapists), paid carers (care workers) in a variety of settings (including residential homes, supported living settings and day services) and educational staff.

Stereotypy

Repeated behaviours, such as rocking or hand flapping, that may appear to have no obvious function but often serve a purpose for the person (for example, to provide sensory stimulation or indicate distress or discomfort).

Treatment manual

Detailed advice and guidance on how to deliver an intervention, including its content, duration and frequency. A treatment manual may also include materials to support the delivery of the intervention for staff and people receiving the intervention.

1.1 General principles of care

Working with people with a learning disability and behaviour that challenges, and their families and carers

1.1.1 Work in partnership with children, young people and adults who have a learning disability and behaviour that challenges, and their family members or carers, and:

- involve them in decisions about care
- support self-management and encourage the person to be independent
- build and maintain a continuing, trusting and non-judgemental relationship
- provide information:

  - about the nature of the person's needs, and the range of interventions (for example, environmental, psychological and pharmacological interventions) and services available to them
  - in a format and language appropriate to the person's cognitive and developmental level (including spoken and picture formats, and written versions in Easy Read style and different colours and fonts)
- develop a shared understanding about the function of the behaviour
- help family members and carers to provide the level of support they feel able to.

1.1.2 When providing support and interventions for people with a learning disability and behaviour that challenges, and their family members or carers:

- take into account the severity of the person's learning disability, their developmental stage, and any communication difficulties or physical or mental health problems
- aim to provide support and interventions:
  - in the least restrictive setting, such as the person's home, or as close to their home as possible, and
  - in other places where the person regularly spends time (for example, school or residential care)
- aim to prevent, reduce or stop the development of future episodes of behaviour that challenges
- aim to improve quality of life
- offer support and interventions respectfully
- ensure that the focus is on improving the person's support and increasing their skills rather than changing the person
- ensure that they know who to contact if they are concerned about care or interventions, including the right to a second opinion
- offer independent advocacy to the person and to their family members or carers.

Understanding learning disabilities and behaviour that challenges

1.1.3 Everyone involved in commissioning or delivering support and interventions for people with a learning disability and behaviour that challenges (including family members and carers) should understand:

- the nature and development of learning disabilities
- personal and environmental factors related to the development and maintenance of behaviour that challenges
- that behaviour that challenges often indicates an unmet need
- the effect of learning disabilities and behaviour that challenges on the person's personal, social, educational and occupational functioning
- the effect of the social and physical environment on learning disabilities and behaviour that challenges (and vice versa), including how staff and carer responses to the behaviour may maintain it.

Delivering effective care

1.1.4 Health and social care provider organisations should ensure that teams carrying out assessments and delivering interventions recommended in this guideline have the training and supervision needed to ensure that they have the necessary skills and competencies.

1.1.5 If initial assessment (see section 1.5) and management have not been effective, or the person has more complex needs, health and social care provider organisations should ensure that teams providing care have prompt and coordinated access to specialist assessment, support and intervention services. These services should provide advice, supervision and training from a range of staff to support the implementation of any care or intervention, including psychologists, psychiatrists, behavioural analysts, nurses, social care staff, speech and language therapists, educational staff, occupational therapists, physiotherapists, physicians, paediatricians and pharmacists.

Staff training, supervision and support

1.1.6 Health and social care provider organisations should ensure that all staff working with people with a learning disability and behaviour that challenges are trained to deliver proactive strategies to reduce the risk of behaviour that challenges, including:

- developing personalised daily activities
- adapting a person's environment and routine
- strategies to help the person develop an alternative behaviour to achieve the same purpose by developing a new skill (for example, improved communication, emotional regulation or social interaction)
- the importance of including people, and their family members or carers, in planning support and interventions
- strategies designed to calm and divert the person if they show early signs of distress
- delivering reactive strategies.

1.1.7 Health and social care provider organisations should ensure that all staff get personal and emotional support to:

- enable them to deliver interventions effectively for people with a learning disability and behaviour that challenges
- feel able to seek help for difficulties arising from working with people with a learning disability and behaviour that challenges
- recognise and manage their own stress.

1.1.8 Health and social care provider organisations should ensure that all interventions for behaviour that challenges are delivered by competent staff. Staff should:

- receive regular high-quality supervision that takes into account the impact of individual, social and environmental factors
- deliver interventions based on the relevant treatment manuals
- consider using routine outcome measures at each contact (for example, the Adaptive Behavior Scale and the Aberrant Behavior Checklist)
- take part in monitoring (for example, by using Periodic Service Review methods)

- evaluate adherence to interventions and practitioner competence (for example, by using video and audio recording, and external audit and scrutiny).

Organising effective care

The recommendations in this section are adapted from the NICE guideline on common mental health disorders.

1.1.9 A designated leadership team of healthcare professionals, educational staff, social care practitioners, managers and health and local authority commissioners should develop care pathways for people with a learning disability and behaviour that challenges for the effective delivery of care and the transition between and within services that are:

- negotiable, workable and understandable for people with a learning disability and behaviour that challenges, their family members or carers, and staff
- accessible and acceptable to people using the services, and responsive to their needs
- integrated (to avoid barriers to movement between different parts of the care pathways)
- focused on outcomes (including measures of quality, service-user experience and harm).

1.1.10 The designated leadership team should be responsible for developing, managing and evaluating care pathways, including:

- developing clear policies and protocols for care pathway operation
- providing training and support on care pathway operation
- auditing and reviewing care pathway performance.

1.1.11 The designated leadership team should work together to design care pathways that promote a range of evidence-based interventions and support people in their choice of interventions.

1.1.12 The designated leadership team should work together to design care pathways that respond promptly and effectively to the changing needs of the people they serve and have:

- clear and agreed goals for the services offered
- robust and effective ways to measure and evaluate the outcomes associated with the agreed goals.

1.1.13 The designated leadership team should work together to design care pathways that provide an integrated programme of care across all care services and:

- minimise the need for transition between different services or providers
- provide the least restrictive alternatives for people with behaviour that challenges
- allow services to be built around the care pathway (and not the other way around)
- establish clear links (including access and entry points) to other care pathways (including those for physical healthcare needs)
- have designated staff who are responsible for coordinating people's engagement with a care pathway and transition between services within and between care pathways.

1.1.14 The designated leadership team should work together to ensure effective communication about the functioning of care pathways. There should be protocols for sharing information:

- with people with a learning disability and behaviour that challenges, and their family members or carers (if appropriate), about their care
- about a person's care with other staff (including GPs)
- with all the services provided in the care pathway
- with services outside the care pathway.

1.2 Physical healthcare

1.2.1 GPs should offer an annual physical health check to children, young people and adults with a learning disability in all settings, using a standardised template (such as the Cardiff health check template)[1]. This should be carried out together with a family member, carer or healthcare professional or social care practitioner who knows the person and include:

- a review of any known or emerging behaviour that challenges and how it may be linked to any physical health problems
- a physical health review
- a review of all current health interventions, including medication and related side effects, adverse events, drug interactions and adherence
- an agreed and shared care plan for managing any physical health problems (including pain).

1.3 Support and interventions for family members or carers

1.3.1 Involve family members or carers in developing and delivering the support and intervention plan for children, young people and adults with a learning disability and behaviour that challenges. Give them information about support and interventions in a format and language that is easy to understand, including NICE's 'Information for the public'.

1.3.2 Advise family members or carers about their right to, and explain how to get:

- a formal carer's assessment of their own needs (including their physical and mental health)
- short breaks and other respite care.

1.3.3 When providing support to family members or carers (including siblings):

- recognise the impact of living with or caring for a person with a learning disability and behaviour that challenges
- explain how to access family advocacy
- consider family support and information groups if there is a risk of behaviour that challenges, or it is emerging
- consider formal support through disability-specific support groups for family members or carers and regular assessment of the extent and severity of the behaviour that challenges

- provide skills training and emotional support, or information about these, to help them take part in and support interventions for the person with a learning disability and behaviour that challenges.

1.3.4 If a family member or carer has an identified mental health problem, consider:

- interventions in line with existing NICE guidelines or
- referral to a mental health professional who can provide interventions in line with existing NICE guidelines.

1.4 Early identification of the emergence of behaviour that challenges

1.4.1 Everyone involved in caring for and supporting children, young people and adults with a learning disability (including family members and carers) should understand the risk of behaviour that challenges and that it often develops gradually. Pay attention to and record factors that may increase this risk, including:

- personal factors, such as:
  - a severe learning disability
  - autism
  - dementia
  - communication difficulties (expressive and receptive)
  - visual impairment (which may lead to increased self-injury and stereotypy)
  - physical health problems
  - variations with age (peaking in the teens and twenties)
- environmental factors, such as:
  - abusive or restrictive social environments
  - environments with little or too much sensory stimulation and those with low engagement levels (for example, little interaction with staff)

  - developmentally inappropriate environments (for example, a curriculum that makes too many demands on a child or young person)
  - environments where disrespectful social relationships and poor communication are typical or where staff do not have the capacity or resources to respond to people's needs
  - changes to the person's environment (for example, significant staff changes or moving to a new care setting).

1.4.2 Consider using direct observation and recording or formal rating scales (for example, the Adaptive Behavior Scale or Aberrant Behavior Checklist) to monitor the development of behaviour that challenges.

1.5 Assessment of behaviour that challenges

The assessment process

1.5.1 When assessing behaviour that challenges shown by children, young people and adults with a learning disability follow a phased approach, aiming to gain a functional understanding of why the behaviour occurs. Start with initial assessment and move on to further assessment if, for example, intervention has not been effective or the function of the behaviour is not clear (see recommendations 1.5.4–1.5.11). Develop a behaviour support plan (see recommendation 1.6.1) as soon as possible.

1.5.2 When assessing behaviour that challenges ensure that:

- the person being assessed remains at the centre of concern and is supported throughout the process
- the person and their family members and carers are fully involved in the assessment process
- the complexity and duration of the assessment process is proportionate to the severity, impact, frequency and duration of the behaviour
- everyone involved in delivering assessments understands the criteria for moving to more complex and intensive assessment (see recommendation 1.5.8)

- all current and past personal and environmental factors (including care and educational settings) that may lead to behaviour that challenges are taken into account
- assessment is a flexible and continuing (rather than a fixed) process, because factors that trigger and maintain behaviour may change over time
- assessments are reviewed after any significant change in behaviour
- assessments are focused on the outcomes of reducing behaviour that challenges and improving quality of life
- the resilience, resources and skills of family members and carers are taken into account
- the capacity, sustainability and commitment of the staff delivering the behaviour support plan (see recommendation 1.6.1) are taken into account.

1.5.3 Explain to the person and their family members or carers how they will be told about the outcome of any assessment of behaviour that challenges. Ensure that feedback is personalised and involves a family member, carer or advocate to support the person and help them to understand the feedback if needed.

Initial assessment of behaviour that challenges

1.5.4 If behaviour that challenges is emerging or apparent, or a family member, carer or member of staff (such as a teacher or care worker), has concerns about behaviour, carry out initial assessment that includes:

- a description of the behaviour (including its severity, frequency, duration and impact on the person and others) from the person (if possible) and a family member, carer or a member of staff (such as a teacher or care worker)
- an explanation of the personal and environmental factors involved in developing or maintaining the behaviour from the person (if possible) and a family member, carer or a member of staff (such as a teacher or care worker)
- the role of the service, staff, family members or carers in developing or maintaining the behaviour.

Consider using a formal rating scale (for example, the Aberrant Behavior Checklist or Adaptive Behavior Scale) to provide baseline levels for the behaviour and a scale (such as the Functional Analysis Screening Tool) to help understand its function.

1.5.5 As part of initial assessment of behaviour that challenges, take into account:

- the person's abilities and needs (in particular, their expressive communication and receptive communication)
- any physical or mental health problems, and the effect of medication, including side effects
- developmental history, including neurodevelopmental problems (including the severity of the learning disability and the presence of autism or other behavioural phenotypes)
- response to any previous interventions for behaviour that challenges
- the impact of the behaviour that challenges on the person's:
  - quality of life and that of their family members or carers
  - independent living skills and educational or occupational abilities
- social and interpersonal history, including relationships with family members, carers, staff (such as teachers) or other people with a learning disability (such as those the person lives with)
- aspects of the person's culture that could be relevant to the behaviour that challenges
- life history, including any history of trauma or abuse
- recent life events and changes to routine
- the person's sensory profile, preferences and needs
- the physical environment, including heat, light, noise and smell
- the care environment, including the range of activities available, how it engages people and promotes choice, and how well structured it is.

1.5.6 After initial assessment, develop a written statement (formulation) that sets out an understanding of what has led to the behaviour that challenges and the function of the behaviour. Use this to develop a behaviour support plan (see recommendation 1.6.1).

Risk assessment

1.5.7 Assess and regularly review the following areas of risk during any assessment of behaviour that challenges:

- suicidal ideation, self-harm (in particular in people with depression) and self-injury
- harm to others
- self-neglect
- breakdown of family or residential support
- exploitation, abuse or neglect by others
- rapid escalation of the behaviour that challenges.

Ensure that the behaviour support plan includes risk management (see recommendation 1.6.1).

Further assessment of behaviour that challenges

1.5.8 If the behaviour that challenges is severe or complex, or does not respond to the behaviour support plan, review the plan and carry out further assessment that is multidisciplinary and draws on skills from specialist services (see recommendation 1.1.5), covering any areas not fully explored by initial assessment (see recommendation 1.5.5). Carry out a functional assessment (see recommendations 1.5.9–1.5.11), identifying and evaluating any factors that may provoke or maintain the behaviour. Consider using formal (for example, the Adaptive Behavior Scale or the Aberrant Behavior Checklist) and idiographic (personalised) measures to assess the severity of the behaviour and the progress of any intervention.

Functional assessment of behaviour

1.5.9 Carry out a functional assessment of the behaviour that challenges to help inform decisions about interventions. This should include:

- a clear description of the behaviour, including classes or sequences of behaviours that typically occur together
- identifying the events, times and situations that predict when the behaviour will and will not occur across the full range of the person's daily routines and usual environments
- identifying the consequences (or reinforcers) that maintain the behaviour (that is, the function or purpose that the behaviour serves)
- developing summary statements or hypotheses that describe the relationships between personal and environmental triggers, the behaviour and its reinforcers
- collecting direct observational data to inform the summary statements or hypotheses.

1.5.10 Include the following in a functional assessment:

- a baseline measurement of current behaviour, and its frequency and intensity, and repeated measurements in order to evaluate change
- measurements including direct observations and scales such as the Aberrant Behavior Checklist and self-reporting
- a baseline measurement of quality of life (such as the Life Experiences Checklist and the Quality of Life Questionnaire)
- assessment of the impact of current or past interventions, including reactive strategies.

1.5.11 Vary the complexity and intensity of the functional assessment according to the complexity and intensity of behaviour that challenges, following a phased approach as set out below.

- Carry out pre-assessment data gathering to help shape the focus and level of the assessment.
- For recent-onset behaviour that challenges, consider brief structured assessments such as the Functional Analysis Screening Tool or Motivation Assessment Scale to identify relationships between the behaviour and what triggers and reinforces it.
- For recent-onset behaviour that challenges, or marked changes in patterns of existing behaviours, take into account whether any significant alterations to the person's

environment and physical or psychological health are associated with the development or maintenance of the behaviour.

- Consider in-depth assessment involving interviews with family members, carers and others, direct observations, structured record keeping, questionnaires and reviews of case records.
- If a mental health problem may underlie behaviour that challenges, consider initial screening using assessment scales such as the Diagnostic Assessment Schedule for the Severely Handicapped-II, Psychiatric Assessment Schedule for Adults with a Developmental Disability or the Psychopathology Instrument for Mentally Retarded Adults and seek expert opinion.

After further assessment

1.5.12 After further assessment, re-evaluate the written statement (formulation) and adjust the behaviour support plan if necessary.

1.6 Behaviour support plan

1.6.1 Develop a written behaviour support plan for children, young people and adults with a learning disability and behaviour that challenges that is based on a shared understanding about the function of the behaviour. This should:

- identify proactive strategies designed to improve the person's quality of life and remove the conditions likely to promote behaviour that challenges, including:
    - changing the environment (for example, reducing noise, increasing predictability)
    - promoting active engagement through structured and personalised daily activities, including adjusting the school curriculum for children and young people
- identify adaptations to a person's environment and routine, and strategies to help them develop an alternative behaviour to achieve the function of the behaviour that challenges by developing a new skill (for example, improved communication, emotional regulation or social interaction)
- identify preventive strategies to calm the person when they begin to show early signs of distress, including:

    - individual relaxation techniques
    - distraction and diversion onto activities they find enjoyable and rewarding

- identify reactive strategies to manage any behaviours that are not preventable (see section 1.9), including how family members, carers or staff should respond if a person's agitation escalates and there is a significant risk of harm to them or others
- incorporate risk management and take into account the effect of the behaviour support plan on the level of risk
- be compatible with the abilities and resources of the person's family members, carers or staff, including managing risk, and can be implemented within these resources
- be supported by data that measure the accurate implementation of the plan
- be monitored using the continuous collection of objective outcome data
- be reviewed frequently (fortnightly for the first 2 months and monthly thereafter), particularly if behaviour that challenges or use of restrictive interventions increases, or quality of life decreases
- identify any training for family members, carers or staff to improve their understanding of behaviour that challenges shown by people with a learning disability
- identify those responsible for delivering the plan and the designated person responsible for coordinating it.

1.7 Psychological and environmental interventions

Early intervention for children and their parents or carers

1.7.1 Consider parent-training programmes for parents or carers of children with a learning disability who are aged under 12 years with emerging, or at risk of developing, behaviour that challenges.

1.7.2 Parent-training programmes should:

- be delivered in groups of 10 to 15 parents or carers
- be accessible (for example, take place outside normal working hours or in community-based settings with childcare facilities)

- focus on developing communication and social functioning
- typically consist of 8 to 12 sessions lasting 90 minutes
- follow the relevant treatment manual
- employ materials to ensure consistent implementation of the programme.

1.7.3 Consider preschool classroom-based interventions for children aged 3–5 years with emerging, or at risk of developing, behaviour that challenges.

1.7.4 Preschool classroom-based interventions should have multiple components, including:

- curriculum design and development
- social and communication skills training for the children
- skills training in behavioural strategies for parents or carers
- training on how to mediate the intervention for preschool teachers.

Interventions for behaviour that challenges

1.7.5 Consider personalised interventions for children, young people and adults that are based on behavioural principles and a functional assessment of behaviour, tailored to the range of settings in which they spend time, and consist of:

- clear targeted behaviours with agreed outcomes
- assessment and modification of environmental factors that could trigger or maintain the behaviour (for example, altering task demands for avoidant behaviours)
- addressing staff and family member or carer responses to behaviour that challenges
- a clear schedule of reinforcement of desired behaviour and the capacity to offer reinforcement promptly
- a specified timescale to meet intervention goals (modifying intervention strategies that do not lead to change within a specified time).

1.7.6 Consider individual psychological interventions for adults with an anger management problem. These interventions should be based on cognitive-behavioural principles and delivered individually or in groups over 15–20 hours.

1.7.7 Do not offer sensory interventions (for example, Snoezelen rooms) before carrying out a functional assessment to establish the person's sensory profile. Bear in mind that the sensory profile may change.

1.7.8 Consider developing and maintaining a structured plan of daytime activity (as part of the curriculum if the person is at school) that reflects the person's interests and capacity. Monitor the effects on behaviour that challenges and adjust the plan in discussion with the person and their family members or carers.

1.8 Medication

1.8.1 Consider medication, or optimise existing medication (in line with the NICE guideline on medicines optimisation), for coexisting mental or physical health problems identified as a factor in the development and maintenance of behaviour that challenges shown by children, young people and adults with a learning disability (see also recommendation 1.10.1).

1.8.2 Consider antipsychotic medication to manage behaviour that challenges only if:

- psychological or other interventions alone do not produce change within an agreed time or
- treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour or
- the risk to the person or others is very severe (for example, because of violence, aggression or self-injury).

Only offer antipsychotic medication in combination with psychological or other interventions.

1.8.3 When choosing which antipsychotic medication to offer, take into account the person's preference (or that of their family member or carer, if appropriate), side effects, response to previous antipsychotic medication and interactions with other medication.

1.8.4 Antipsychotic medication should initially be prescribed and monitored by a specialist (an adult or child psychiatrist or a neurodevelopmental paediatrician) who should:

- identify the target behaviour
- decide on a measure to monitor effectiveness (for example, direct observations, the Aberrant Behavior Checklist or the Adaptive Behavior Scale), including frequency and severity of the behaviour and impact on functioning
- start with a low dose and use the minimum effective dose needed
- only prescribe a single drug
- monitor side effects as recommended in the NICE guidelines on psychosis and schizophrenia in adults and psychosis and schizophrenia in children and young people
- review the effectiveness and any side effects of the medication after 3–4 weeks
- stop the medication if there is no indication of a response at 6 weeks, reassess the behaviour that challenges and consider further psychological or environmental interventions
- only prescribe p.r.n. (as-needed) medication for as short a time as possible and ensure that its use is recorded and reviewed
- review the medication if there are changes to the person's environment (for example, significant staff changes or moving to a new care setting) or their physical or mental health.

1.8.5 Ensure that the following are documented:

- a rationale for medication (explained to the person with a learning disability and everyone involved in their care, including their family members and carers)
- how long the medication should be taken for
- a strategy for reviewing the prescription and stopping the medication.

1.8.6 If there is a positive response to antipsychotic medication:

- record the extent of the response, how the behaviour has changed and any side effects or adverse events
- conduct a full multidisciplinary review after 3 months and then at least every 6 months covering all prescribed medication (including effectiveness, side effects and plans for stopping)
- only continue to prescribe medication that has proven benefit.

1.8.7 When prescribing is transferred to primary or community care, or between services, the specialist should give clear guidance to the practitioner responsible for continued prescribing about:

- which behaviours to target
- monitoring of beneficial and side effects
- taking the lowest effective dose
- how long the medication should be taken for
- plans for stopping the medication.

1.8.8 For the use of rapid tranquillisation, follow the NICE guideline on violence and aggression.

1.9 Reactive strategies

1.9.1 Only use reactive strategies for children, young people and adults with a learning disability and behaviour that challenges as a last resort and together with the proactive interventions described in section 1.7. When risks to the person with a learning disability or others are significant, or breakdown in their living arrangements is very likely, consider using reactive strategies as an initial intervention and introduce proactive interventions once the situation stabilises.

1.9.2 Ensure that reactive strategies, whether planned or unplanned, are delivered on an ethically sound basis. Use a graded approach that considers the least restrictive alternatives first. Encourage the person and their family members or carers to be involved in planning and reviewing reactive strategies whenever possible.

1.9.3 If a restrictive intervention is used as part of a reactive strategy, follow the NICE guideline on violence and aggression for the safe use of restrictive interventions and carry out a thorough risk assessment. Take into account:

- any physical health problems and physiological contraindications to the use of restrictive interventions, in particular manual and mechanical restraint
- any psychological risks associated with the intervention, such as a history of abuse
- any known biomechanical risks, such as musculoskeletal risks
- any sensory sensitivities, such as a high or low threshold for touch.

Document and review the delivery and outcome of the restrictive intervention and discuss these with everyone involved in the care of the person, including their family members and carers, and with the person if possible.

1.9.4 Ensure that any restrictive intervention is accompanied by a restrictive intervention reduction programme, as part of the long-term behaviour support plan, to reduce the use of and need for restrictive interventions.

1.9.5 Ensure that planned restrictive interventions:

- take place within the appropriate legal framework of the Human Rights Act 1998, the relevant rights in the European Convention on Human Rights, the Mental Health Act 1983 and the Mental Capacity Act 2005, including the supplementary code of practice on deprivation of liberty safeguards
- are in the best interest of the person to protect them or others from immediate and significant harm
- are a reasonable, necessary and proportionate response to the risk presented.

1.9.6 Regularly review and reassess the safety, efficacy, frequency of use, duration and continued need for reactive strategies, including restrictive interventions (follow the NICE guideline on violence and aggression for the safe use of restrictive interventions). Document their use as part of an incident record and use this in personal and organisational debrief procedures to inform future behaviour support planning and organisational learning.

1.10 Interventions for coexisting health problems

1.10.1 Offer children, young people and adults with a learning disability and behaviour that challenges interventions for any suspected or coexisting mental or physical health problems in line with the relevant NICE guideline for that condition (see also recommendation 1.8.1). Adjust the nature, content and delivery of the interventions to take into account the impact of the person's learning disability and behaviour that challenges.

1.11 Interventions for sleep problems

1.11.1 Consider behavioural interventions for sleep problems in children, young people and adults with a learning disability and behaviour that challenges that consist of:

- a functional analysis of the problem sleep behaviour to inform the intervention (for example, not reinforcing non-sleep behaviours)
- structured bedtime routines.

1.11.2 Do not offer medication to aid sleep unless the sleep problem persists after a behavioural intervention, and then only:

- after consultation with a psychiatrist (or a specialist paediatrician for a child or young person) with expertise in its use in people with a learning disability
- together with non-pharmacological interventions and regular reviews (to evaluate continuing need and ensure that the benefits continue to outweigh the risks).

If medication is needed to aid sleep, consider melatonin[2].

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[1] See the Royal College of General Practitioners' guide for GP practices on annual health checks for people with a learning disability for further information.

[2] At the time of publication (May 2015), melatonin did not have a UK marketing authorisation for use in people aged under 55 years for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

2 Research recommendations

The Guideline Development Group has made the following recommendations for research, based on its review of evidence, to improve NICE guidance and the care and treatment people receive in the future.

2.1 Preventing behaviour that challenges from developing in children aged under 5 years with a learning disability

Can positive behaviour support provided for children aged under 5 years with a learning disability reduce the risk of developing behaviour that challenges?

Why this is important

Behaviour that challenges is common in children with a learning disability and can have a considerable impact on them and their family members or carers. It is a common reason for residential placement with associated high costs. Positive behaviour support aims to reduce behaviour that challenges and increase quality of life through teaching new skills and adjusting the environment to promote positive behaviour changes. Early intervention with children at risk of developing behaviour that challenges offers an opportunity to significantly enhance their life and that of their family members or carers.

The question should be addressed by a programme of research that includes:

- developing interventions to prevent behaviour that challenges from developing in children aged under 5 years
- assessing the feasibility of the formal evaluation of the interventions in a randomised controlled trial
- testing the clinical and cost effectiveness of the interventions in a large scale randomised controlled trial with long-term follow-up
- evaluating the implementation of the interventions in routine care.

2.2 Interventions to reduce the frequency and extent of moderate to severe behaviour that challenges in community settings

Are interventions based on the science and practice of applied behaviour analysis or antipsychotic medication, or a combination of these, effective in reducing the frequency and severity of behaviour that challenges shown by adults with a learning disability?

Why this is important

Behaviour that challenges is common in adults with a learning disability and can have a considerable impact on them and their family members or carers. It is also a common reason for hospital or residential placement. There is limited evidence for the effectiveness of either applied behaviour analysis or antipsychotic medication, or a combination of these in community settings. Little is known about which people respond best to which interventions or about the duration of the interventions. There is considerable evidence of the over use of medication and of limited skills and competence in delivering behavioural interventions.

The question should be addressed by a programme of research evaluating these interventions that includes:

- developing a protocol for assessing moderate to severe behaviour that challenges that:
    - characterises the nature and function of the behaviour
    - assesses all coexisting problems that may contribute to the behaviour developing or being maintained
- developing protocols for delivering and monitoring the interventions to be tested (including how any currently provided interventions will be stopped)
- assessing the feasibility of the formal evaluation of the interventions in a randomised controlled trial (in particular, recruitment)
- testing the comparative clinical effectiveness (including moderators and mediators) and cost effectiveness of the interventions in a large-scale randomised controlled trial.

2.3 *Locally accessible care*

Does providing care where people live compared with out-of-area placement lead to improvements in both the clinical and cost effectiveness of care for people with a learning disability and behaviour that challenges?

Why this is important

Many out-of-area care placements for people with a learning disability and behaviour that challenges are a long way from their home. This can have a considerable impact, limiting a family member or carer's ability to care for the person and leading to poorer outcomes and increased costs. It is widely recognised that locally accessible care settings could be beneficial and could reduce costs but there is no strong empirical evidence to support this. In the absence of such evidence significant numbers of out-of-area care placements continue to be made.

The question should be addressed by a programme of research that includes:

- a needs assessment and the care costs of a consecutive cohort of 250 people who have been placed in out-of-area care in a 2-year period
- developing standards for a range of support programmes designed to meet people's needs, which would provide detailed information on:
    - the needs to be meet
    - the nature of the care environments
    - the support, including specialist staff, needed
- testing the clinical and cost effectiveness of 'close to home' or home-based care that meet the developed standards (compared with consecutive cohorts in out-of-area placements).

2.4 *Factors associated with sustained, high-quality residential care*

What factors (including service organisation and management, staff composition, training and supervision, and the content of care and support) are associated with sustained high-quality residential care for people with a learning disability and behaviour that challenges?

Why this is important

The quality of residential care for people with a learning disability and behaviour that challenges remains an issue of national concern. Reviews (most recently of Winterbourne View Hospital) have identified failings in care. Although recommendations have been made this has not led to a significant and sustained improvement in care. It is important to understand how improvement can be maintained.

The question should be addressed by a programme of research that includes:

- a systematic review of the factors associated with sustained and beneficial change in health and social care organisations
- designing service-level interventions to support the implementation of standards of care developed from the systematic review
- testing the clinical and cost effectiveness of service-level interventions in residential units through the formal evaluation of a quality improvement programme established to introduce the new standards (the follow-up period should be for a minimum of 3 years after the implementation of the intervention).

3 Other information

3.1 *Scope and how this guideline was developed*

NICE guidelines are developed in accordance with a scope that defines what the guideline will and will not cover.

How this guideline was developed

NICE commissioned the National Collaborating Centre for Mental Health to develop this guideline. The Centre established a Guideline Development Group (see section 4), which reviewed the evidence and developed the recommendations.

The methods and processes for developing NICE clinical guidelines are described in the guidelines manual.

3.2 *Related NICE guidance*

Details are correct are correct at the time of publication of the guideline (May 2015). Further information is available on the NICE website.

Published

General

- Medicines optimisation (2015) NICE guideline NG5
- Patient experience in adult NHS services (2012) NICE guideline CG138
- Service user experience in adult mental health (2011) NICE guideline CG136
- Medicines adherence (2009) NICE guideline CG76

Condition-specific

- Violence and aggression (2015) NICE guideline NG10
- Psychosis and schizophrenia in adults (2014) NICE guideline CG178
- Autism: the management and support of children and young people on the autism spectrum (2013) NICE guideline CG170

- Antisocial behaviour and conduct disorders in children and young people (2013) NICE guideline CG158
- Psychosis and schizophrenia in children and young people (2013) NICE guideline CG155
- Autism: recognition, referral, diagnosis and management of adults on the autism spectrum (2012) NICE guideline CG142
- Self-harm: longer term management (2011) NICE guideline CG133
- Autism diagnosis in children and young people (2011) NICE guideline CG128
- Common mental health disorders (2011) NICE guideline CG123
- Attention deficit hyperactivity disorder (2008) NICE guideline CG72
- Dementia (2006) NICE guideline CG42
- Self-harm (2004) NICE guideline CG16

Under development

NICE is developing the following guidance:

- Children's attachment. NICE guideline. Publication expected October 2015.
- Mental health problems in people with learning disabilities. NICE guideline. Publication expected September 2016.

4 The Guideline Development Group, National Collaborating Centre and NICE project team, and declarations of interests

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4.4 Declarations of interests

The following members of the Guideline Development Group made declarations of interests. All other members of the Group stated that they had no interests to declare. The conflicts of interest policy (2007) was followed until September 2014, when an updated policy was published.

Member	Interest declared	Type of interest	Decision taken
Glynis Murphy (Chair)	Until October 2012 employed part-time by NHS. Conduct consultancy for NHS, police, lawyers. Co-editor Journal of Applied Research in Intellectual Disability. Member Care Quality Commission panel. Member National Offender Management Service accreditation panel.	Personal pecuniary interest	Declare and participate
Glynis Murphy (Chair)	Co-director Tizard Centre in receipt of grants (National Institute for Health Research/ charities). Tizard Centre training for staff from Learning Disabilities. Tizard Centre research grant; treatment of sexually abusive behaviour in young people with a learning disability.	Non-personal pecuniary interest	Declare and participate
Glynis Murphy (Chair)	Conducted own research into challenging behaviour. Chair Sexual Offender Treatment South East Collaborative-Intellectual Disability Immediate Past President International Association for the Scientific Study of Intellectual and Developmental Disabilities.	Personal non-pecuniary interest	Declare and participate

Steve Pilling (Facilitator)	Medical Research Council, research funding looking at psilocybin. Grant from National Alliance for Research on Schizophrenia and Depression to look at transcranial direct-current stimulation in treatment of depression.	Personal family interest	Declare and participate
David Allen	Positive Response Training and Consultancy provides training to health and social care staff and families supporting people with learning disabilities and challenging behaviour. It uses an over-arching positive behaviour support model and provides training in both proactive, preventative strategies and reactive strategies. The physical intervention training component of the latter is accredited by the British Institute of Learning Disabilities. Editor of International Journal of Positive Behavioural Support. Collaborator in randomised controlled trial of Training in Positive Behavioural Support (Hassiotis, 2013). Joint applicant, Reduction in Anti-psychotic Medication in People with Learning Disability and Challenging Behaviour (Kerr, Felce 2013).	Personal pecuniary interest	Declare and participate
David Allen	Honorary Professor, University of Kent	Non-personal pecuniary interest	Declare and participate
David Allen	Member of various working groups set up as part of Positive and Safe Programme. Member of Positive and Safe Programme Board. Member of group that recently produced competence framework for positive behaviour support.	Personal non-pecuniary interest	Declare and participate

David Brandford	Development of guideline on dysphagia in learning disabilities supported by Rosemont Pharmaceuticals. Opinion on lisdexamphetamine supported by Pharmacy management. Opinion on lurasidone supported by Sunovion Pharmaceuticals.	Personal pecuniary interest	Declare and participate
David Brandford	PhD on antipsychotic drugs in learning disabilities. Chairman of the English Pharmacy Board of the Royal Pharmaceutical Society. Elected member of the College of Mental Health Pharmacy. Editor of Frith prescribing guidelines for adults with learning disability (no financial interest).	Non-personal pecuniary interest	Declare and participate
Alick Bush	Employed 0.6 whole time equivalent by St Andrews Healthcare, a charity that provides inpatient care to adults with learning disabilities and autism. Provides a clinical psychology service to patients in the hospital.	Personal pecuniary interest	Declare and participate

Alick Bush	Policy lead, British Psychological Society Faculty of Learning Disabilities – promoted the use of predominantly psychosocial interventions for adults who challenge services, including positive behaviour support. Until December 2014, Chair of the Learning Disabilities Professional Senate – an alliance of the Professional Bodies that provide support to people with learning disabilities. Representative of the Professional Senate on the Learning Disability Programme Board. On a range of sub-committees and working groups that are responsible for delivering the Transforming Care action plan following the Winterbourne View review. This includes being a member of the Expert Advisory Group on the promotion of positive behaviour support. Co-editor of Challenging Behaviour: a unified approach. Acted as a special advisor on a Care Quality Commission inspection.	Personal non-pecuniary interest	Declare and participate
Carole Buckley	Non-Executive Director GP Care (UK) Ltd. Private provider of NHS services to patients. Chair St Mathias holdings Ltd Practice based pharmacy offering services to residential care homes.	Personal pecuniary interest	Declare and participate

Carole Buckley	Member Royal College of General Practitioners intellectual disability professional network. Clinical Champion for Autism by the Royal College of General Practitioners. Joint recipient of a grant from Bristol University to implement focus groups for service users and carers in order to inform GP practice. Grant from the Academic Health Science Network South West to hold a conference in Taunton 19/11/14 for commissioners and providers of autism services.	Non-personal pecuniary interest	Declare and participate

Vivien Cooper	Member, Transforming Care Assurance Board (formerly Winterbourne View Joint Improvement Board). Member, Engagement Steering Group for Joint Improvement team (from June 2014 formerly Chair). Respond Steering Group for support for Winterbourne View families. Department of Health Advocacy Group. Department of Health Medication Collaborative Group, Steering Group. Care Quality Commission Learning Disability Advisory Group. Hassiotis University College London Positive Behaviour Support Research Group. Tizard E-Pats Fellowship Steering Group. Chair, Challenging Behaviour National Strategy Group. Member, Council for Disabled Children Restrictive Physical Intervention Steering Group. Member, Department of Health Winterbourne View Capital Funding Panel. Member, Learning Disabilities Professional Senate. Member, School for Social Care Research User Carer Practitioner Reference Group. Member, Learning Disabilities Voluntary and Community Sectors Steering Group (July – November 2014). Member, Children and Young People Collaborative Steering Group.	Personal non-pecuniary interest	Declare and participate

Angela Hassiotis	Current National Institute for Health Research Health Technology Assessment grant on the evaluation of positive behaviour support. Honoraria received by Novartis for consultancy on treatments for Fragile X syndrome. Other research funding (National Institute for Health Research – Research for Patient Benefit). Associate Editor of Journal of Policy and Practice in Intellectual and Developmental Disabilities. Associate Editor of Journal of Applied Research in Intellectual Disabilities. Editorial Board of Advances in Mental Health Intellectual Disabilities. Treasurer Faculty of the Psychiatry of Intellectual Disabilities. Honoraria for lectures. Conducting a study looking at music therapy and people with a learning disability. Co-applicant on a National Institute for Health Research Health Technology Assessment funded study evaluating music therapy for children with autism.	Non-personal pecuniary interest	Declare and participate
Angela Hassiotis	Published on challenging behaviour for some years following research carried out under own supervision.	Personal non-pecuniary interest	Declare and participate
Simon Jones	Positive Range of Options to Avoid Crisis and use Therapy, Strategies for Crisis Intervention and Prevention (PROACT-SCIPr-UK) trainer, which is a British Institute of Learning Disabilities accredited physical intervention methodology.	Personal pecuniary interest	Declare and participate

Richard Mills	Research Director at Research Autism. AT-Autism (Autism Training Ltd) – Associate. London Borough of Redbridge – training in clinical interviewing techniques for Approved Mental Health Professionals when working with individuals with Asperger's syndrome and autism in conjunction with AT-Autism. Laskaridou Foundation Athens, Greece – Mentor teacher programme for children with autism and challenging behaviour in conjunction with AT-Autism. Associate, Tizard Centre, University of Kent at Canterbury – Curriculum development Social Work Training.	Personal pecuniary interest	Declare and participate
Richard Mills	Joint recipient of a grant from Bristol University to implement focus groups for service users and carers in order to inform GP practice. Staff training Jersey Employment Trust –through Research Autism.	Non-personal pecuniary interest	Declare and participate
Richard Mills	Fellow – Royal Society of Medicine. Member – International Society for Autism Research. Honorary Research Fellow at the Department of Psychology, University of Bath. Senior Research Fellow, Bond University, Queensland, Australia. Member – Northern Ireland Advisory Committee on Autism Research.	Personal non-pecuniary interest	Declare and participate
David Newton	Employed by a local authority; involves liaison with local authority and local clinical commissioning group contracts and commissioning groups and quality assurance. Some incidental input into local authority core contract and service specification content.	Personal pecuniary interest	Declare and participate

Victoria Slonims	Autism Diagnostic Observation Schedule trainer.	Personal pecuniary interest	Declare and participate
Craig Whittington	Member of the scientific steering committee for a US company, Doctor Evidence Llc. Doctor Evidence is a specialty software platform and services company with clients from across the healthcare ecosystem. The role includes a share option (3 year vesting) and a meeting stipend.	Personal pecuniary interest	Declare and participate
Keith Wyncoll	Occasional trainer – The Challenging Behaviour Foundation. Lay member of NHS England Patient and Public Voice Assurance Group – Specialised Commissioning.	Personal pecuniary interest	Declare and participate

About this guideline

NICE clinical guidelines are recommendations about the treatment and care of people with specific diseases and conditions.

NICE guidelines are developed in accordance with a scope that defines what the guideline will and will not cover.

This guideline was developed by the National Collaborating Centre for Mental Health, which is based at the Royal College of Psychiatrists. The Collaborating Centre worked with a Guideline Development Group, comprising healthcare professionals (including consultants, GPs and nurses), carers and technical staff, which reviewed the evidence and drafted the recommendations. The recommendations were finalised after public consultation.

The methods and processes for developing NICE clinical guidelines are described in the guidelines manual.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Strength of recommendations

Some recommendations can be made with more certainty than others. The Guideline Development Group makes a recommendation based on the trade-off between the benefits and harms of an intervention, taking into account the quality of the underpinning evidence. For some interventions, the Guideline Development Group is confident that, given the information it has looked at, most people would choose the intervention. The wording used in the recommendations in this guideline denotes the certainty with which the recommendation is made (the strength of the recommendation).

For all recommendations, NICE expects that there is discussion with the person about the risks and benefits of the interventions, and their values and preferences. This discussion aims to help them to reach a fully informed decision (see also person-centred care).

Interventions that must (or must not) be used

We usually use 'must' or 'must not' only if there is a legal duty to apply the recommendation. Occasionally we use 'must' (or 'must not') if the consequences of not following the recommendation could be extremely serious or potentially life threatening.

Interventions that should (or should not) be used – a 'strong' recommendation

We use 'offer' (and similar words such as 'refer' or 'advise') when we are confident that, for the vast majority of people, an intervention will do more good than harm, and be cost effective. We use similar forms of words (for example, 'Do not offer…') when we are confident that an intervention will not be of benefit for most people.

Interventions that could be used

We use 'consider' when we are confident that an intervention will do more good than harm for most people, and be cost effective, but other options may be similarly cost effective. The choice of intervention, and whether or not to have the intervention at all, is more likely to depend on the person's values and preferences than for a strong recommendation, and so the healthcare professional should spend more time considering and discussing the options with the person.

Other versions of this guideline

The full guideline, 'Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges' contains details of the methods and evidence used to develop the guideline. It is published by the National Collaborating Centre for Mental Health.

The recommendations from this guideline have been incorporated into a NICE pathway.

We have produced information for the public about this guideline.

NICE has produced an Easy Read version for people with a learning disability.

Implementation

Implementation tools and resources to help you put the guideline into practice are also available.

Your responsibility

This guidance represents the view of NICE, which was arrived at after careful consideration of the evidence available. Healthcare professionals are expected to take it fully into account when exercising their clinical judgement. However, the guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer, and informed by the summaries of product characteristics of any drugs.

Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this guidance should be interpreted in a way that would be inconsistent with compliance with those duties.

ISBN 978-1-4731-1232-2

Accreditation

NICE accredited

www.nice.org.uk/accreditation

NHS
England

Stopping over medication of people with learning disabilities, autism or both

Dr Dominic Slowie
National Clinical Advisor
Learning Disability & Premature Mortality

18th January 2017

Why is this a problem?
What are we here to solve?

- Public Health England estimates that every day 30,000 to 35,000 adults with a learning disability are being wrongly prescribed an psychotropic drug
- None of theses people have a documented mental health diagnosis
- Chemical Restraint?
- Most of these prescriptions were initiated in secondary care
- Most of these people have no follow up in secondary care

BRS…..and the New Model

Building the right support

A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition

October 2015

9 Principles

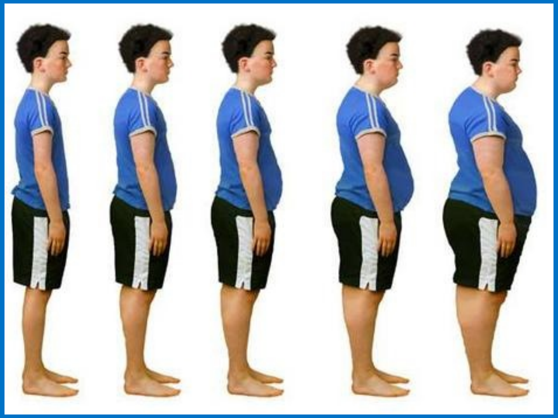
1. Meaningful Life
2. Person centred proactive care
3. Choice and Control
4. Carers are supported
5. Choice about where and who I live with
6. Mainstream services work too
7. Specialist support…In the Community
8. Preventative support
9. In ATU high quality, short time

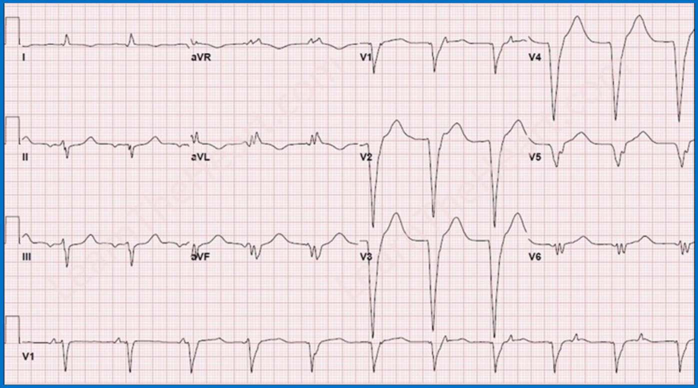
Is this man ill?

“My sister has a tantrum and they say she is cross because she doesn't get enough pocket money. I get cross and they phone the psychiatrist”

Sheila Hollins BJPsych 2000

Side Effects





There’s a Nice Guideline & Quality Standard

- **NICE guideline [NG11] Published date: May 2015 ‘Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges’**

- https://www.nice.org.uk/guidance/ng11

A human rights issue

- If you are drugged up, you can't communicate with people properly
- The world passes you by
- It's a way of restraining people
- It can make your behaviour more challenging in the long run
- It doesn't help you learn or change
- It doesn't help you get out of hospital, the opposite in fact
- People shouldn't be living like that

STOPPING OVER-MEDICATION OF PEOPLE WITH LEARNING DISABILITIES

(STOMPwLD) 2016

https://www.england.nhs.uk/wp-content/uploads/2016/06/stopping-over-medication.pdf

A Pledge from Royal Colleges

- to “work together, and with people with a learning disability and their loved ones, to take real and measurable steps to stop over-medication”
- “Reducing use of powerful drugs whenever we can is a good thing. We have managed this successfully in dementia; it’s now time to bring similar benefits to patients who have a learning disability.”

Professor Sir Bruce Keogh

Making a start

- Is there a viable alternative to medication?
- What might be causing the behaviour?
- Anticipate fears and challenges:
  - ‘We have just got her stable’
  - ‘We are just getting him ready to move on’
  - ‘We need to give her time to adapt to the community’
  - ‘Everything is currently going well - don’t rock the boat’
- NTW Positive Behaviour Support team carrying out a pilot project regarding implementation of the toolkit in general practice

Sunderland Baseline Results - 1

- **1691 patients** on Learning Disability register and NOT on Mental Health register –

Of these patients:-

- 650 may be using psychotropic drugs and antiepileptics inappropriately and may need a review
- 174 are under Mental Health supervision
- 60 discharged from Mental Health services in last 12 months

Sunderland Baseline Results - 2

Of the medication prescribed:-

- **13% (128) initiated in primary care**
- 65% (635) initiated in secondary care
- 22% (213) initiation unknown – not clear in patient’s record
- Only 3.5% (35) have had a trial withdrawal in last 24 months

Key Contacts in Sunderland

- Medicines Optimisation Team sunccg.mo@nhs.net

- Linda Reiling, Joint Commissioning Manager Mental Health & Learning Disabilities linda.reiling@nhs.net

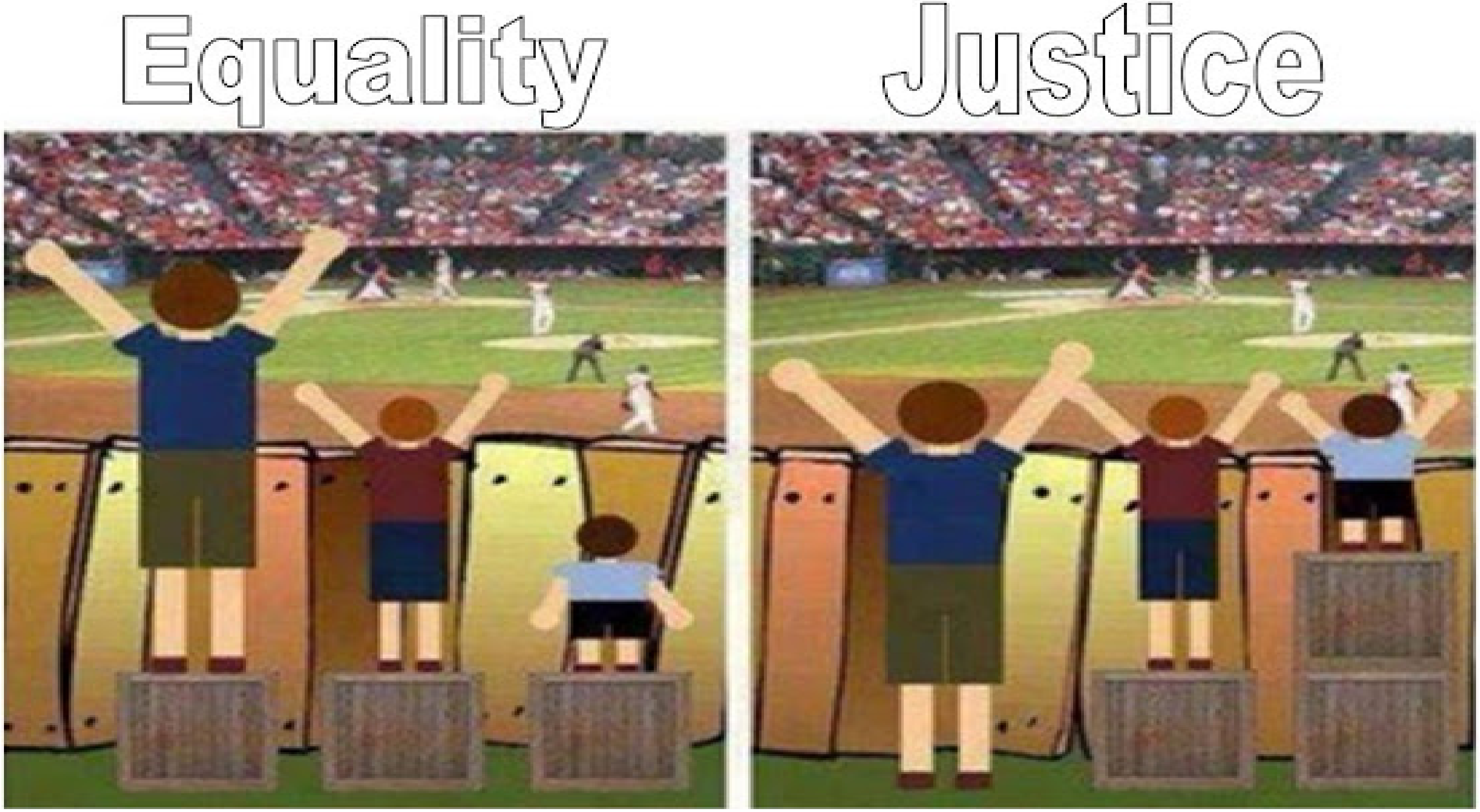
- Ashley Murphy & Jennifer Burn, Sunderland Primary Care Facilitators ashley.murphy@ntw.nhs.uk & jennifer.burn@ntw.nhs.uk

The time to start reducing the use of psychotropic drugs is now

You can do it

- A study in 2014 looked at the effects of controlled withdrawal of antipsychotics used for challenging behaviour
- 98 people took part
- 43 people were successful in stopping completely
- At follow-up only 7 people had been put back on antipsychotics

Effects of controlled discontinuation of long-term used antipsychotics for behavioural symptoms in individuals with intellectual disability
de Kuijper G1, Evenhuis H, Minderaa RB, Hoekstra PJ. (2012). Intellect Disabil Res. 2014 Jan; 58(1):71-83



Offering Two Boxes

What next?

- Ask the question at AHC
- Look out for test practice pilot results
- Seek support from Medicine Optimisation Team
- Small changes over time add up

NHS England

Thank you

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@dominicslowie

NHS England

Publications Gateway Reference 03689

14 July 2015

Dear colleague

The use of medicines in people with learning disabilities

In December 2012, the Department of Health (DH) publication “Transforming Care: A national response to Winterbourne View Hospital” stated that:

“7.31 We have heard deep concerns about the over-use of antipsychotic and antidepressant medicines. Health professionals caring for people with learning disabilities should assess and keep under review the medicines requirements for each individual to determine the best course of action for that patient, taking into account the views of the person wherever possible and their family and/or carer(s). Services should have systems and policies in place for that patient to ensure that this is done safely and in a timely manner and should carry out regular audits of medication prescribing and management, involving pharmacists, doctors and nurses”

When used appropriately, and where there is a clear diagnosis of, for example, psychosis, these medicines can contribute effectively to the treatment of people, including those with learning disability. Medicines such as anticonvulsants are vital to controlling debilitating seizures. However, all these medicines have powerful effects, often with serious side effects. So when they are used, a careful assessment of the risks and benefits must be undertaken. However, and worse of all, some of these medicines can be used wholly inappropriately, as a “chemical restraint” to control behaviour, in place of other more appropriate treatment options.

Unfortunately there is not much evidence to guide practice in this area. Despite a very recent and thorough analysis of the evidence by NICE it would appear that the limited evidence that does exist around adverse effects of antipsychotic treatment in this population reflect the concerns about use in adults with schizophrenia.

The Maudsley Guideline[1] reports on one very large systematic review which quantified risks and benefits of maintenance antipsychotics. The results described

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[1] Taylor D, Paton C, Kapur S. The Maudsley *Prescribing Guidelines in Psychiatry* - 12th edition. Wiley Blackwell

below equate to the following for every 100 adult patients treated with an antipsychotic agent for schizophrenia:

- six will develop movement disorder;
- 10 will develop anticholinergic effects;
- five will develop sedation; and
- five will develop weight gain.

Close links between the use of antipsychotics, stroke and mortality have been reported in patients with dementia[2,3]. We do not know the extent to which we can extrapolate the findings of studies into side effects of antipsychotics in people with schizophrenia and people with dementia but they are not without risks and are likely to cause significant harm for some individuals with learning disability.

As a consequence of the deep concerns of inappropriate use of these medicines, NHS England gathered together a group of carers, health professionals, policy makers and others to develop together a programme of work aimed at understanding the scale and appropriateness of the use of antipsychotic, antidepressant, anxiolytic, hypnotic and antiepileptic medicines.

The group commissioned three pieces of work:

1. an examination of prescribing of these medicines in primary care by Public Heath England (PHE);
2. partnership working with six project sites in England to further understand process and pathways to test new ways of working by NHS Improving Quality (NHS IQ); and
3. an audit of Second Opinion Authorised Doctor information on use of medicines in people detained under the Mental Health Act by the Care Quality Commission (CQC).

Examination of primary care prescribing

This work has identified a high level of inappropriate use of psychotropic drugs in people with learning disabilities.

The study used GP records from the Clinical Practice Research Datalink. This is a well-established system that collects comprehensive, anonymised, clinical data from a large number of general practices throughout the UK for research studies. It covers roughly 8% of the population of England and the data it provides is considered to give a good representation of practice in England.

Among adults known to their GP to have learning disabilities, excluding only those in hospital as inpatients, on any average day, 17.0% were being prescribed antipsychotic drugs, 16.9% antidepressants, 7.1% drugs used in mania and hypomania, 4.2% anxiolytics, and 2.7% hypnotics 2.7%. Nearly one third (29.5%) of

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[2] Banerjee S: *The use of antipsychotic medication for people with dementia: Time for action.* A report for the Minister of State for Care Services: Department of Health; November 2009.

[3] Douglas I*: Exposure to antipsychotics and risk of stroke: self-controlled case* series study: BMJ 2008;337:a1227

all adults known to have learning disabilities were receiving one or more of these types of drug.

These figures, particularly those for antipsychotics and antidepressants are much higher than the prevalence of psychotic conditions or affective disorders established from research studies and increase progressively with age.

58% of adults receiving antipsychotics and 32% of those receiving antidepressants had no relevant diagnosis recorded. 22.5% of prescriptions for antipsychotics included more than one drug in this class and 5.5% were for doses exceeding the recommended maximum. Based on these figures the authors estimated that on an average day in England, between 30,000 and 35,000 adults with a learning disability are being prescribed an antipsychotic, an antidepressant or both without appropriate clinical indications (psychosis or affective disorder). This is 16.2% of the adult population known to their GP as having a learning disability.

Rates of prescribing to adults with autism were also high, though the pattern was less clear as numbers were much smaller. Prescribing of drugs acting on the central nervous system to children and young people with learning disabilities and autism was much less common but also had worrying features.

We recognise that these medicines are typically initiated by specialist doctors and only very rarely by general practitioners. Whilst the responsibility for prescribing lies with the practitioner who signs the prescription, it is critical that GPs and specialists work together, through shared care arrangements, to monitor and regularly review patients taking these powerful medicines.

A report of the study is published by PHE on the Learning Disabilities Team website (www.ihal.org.uk).

Pilot improvement project

This project examined medicines practices and related matters in six sites across England which provide care for people with learning disabilities. The staff at each site worked with experts from NHS IQ, carrying out a “deep dive” into their practice. Whilst many examples of good practice were found, there were also some common themes for improvement. For example, patients, carers or families did not always know why medicines had been prescribed and there was evidence of inadequate communication. On the other hand, there was evidence of the benefits, for example multidisciplinary working, and in particular the deployment of clinical pharmacy expertise. The full report has been published by NHS IQ and can be found at www.nhsiq.nhs.uk/winterbourne.

Second Opinion Authorised Doctor information

The CQC has access to data on medication prescribed to people with learning disabilities detained under the Mental Health Act (1983) and who require a second opinion for treatment with medication for mental health, under the provisions of that Act. The data arise from the work of Second Opinion Appointed Doctors (SOADs) who provide a statutory safeguard for such patients. SOADs visit the patient and explore the current and proposed treatment, certifying what is considered to be appropriate and reasonable in circumstances where the patient cannot or does not consent to it, discussing it with team members and the patient before reaching their conclusions.

The treatment plan is submitted to the CQC when the Second Opinion request is made by the provider clinician. These plans, comprising the types and doses of medication and the reasons given by the doctor for the prescription, together with information provided about the patient's diagnosis, were compared with information and guidelines in the British National Formulary (BNF). It must be recognised that the BNF is a guide, and may be departed from if there are sound reasons. Similarly, many of the medications used in learning disability and considered professionally appropriate may not be specifically licensed for this population and the indications described in the BNF may not cover applicability in this field. This is because the research is relatively limited, and medication manufacturers do not commonly submit information on Learning Disability usage in their product licence application. As a consequence such use may not be cited in the BNF. As an example, autism is not a BNF-recognised indication for prescribing antidepressants, however it is one for which they are widely used according to the literature, though evidence of efficacy is limited. In this survey autism appeared to be a distinct reason for antidepressant use.

The survey identified 945 requests representing 796 individual patients across a 10 month period – some 10% of the total Second Opinion requests submitted in that period. 2/3 were male, mean age 34 yrs. 53% were being treated by an NHS provider, 47% by an independent.

Over half of the prescriptions did not overtly match the accepted indications by reference to the diagnosis. There is published work from specialists in learning disability giving detailed suggestions on medication applicability, however matching these against the data was outside the scope of this survey.

Private hospitals had a higher proportion of patients' prescriptions featuring multiple simultaneous medications of similar type, and in higher doses, compared with NHS hospitals; it is not yet apparent whether this relates to differences in practice, or arises from commissioners referring different diagnostic and prognostic patient groups to different provider types.

In a significant number of cases medication appeared to be prescribed primarily to manage behaviour that was perceived as challenging rather than for symptoms of mental illness.

While the provider's treatment rationale provided some clarification for medication use by expanding on the patient's presentation, in general there was limited rationale offered for the entirety of the treatment plan, particularly when polypharmacy and high dosage was used.

The intervention of the SOAD made changes to the overall treatment plan in some 25% of cases, commonly by restricting the dose total or number of preparations permitted to be used.

The full report will be published by CQC in September.

Next steps

These three reports provide robust evidence of inappropriate use of powerful medicines in people with learning disabilities. This is not acceptable practice and must improve.

To address this we intend to build on the success of a call to action to reduce antipsychotics in dementia by applying a similar collaborative approach to reducing inappropriate use of these and other powerful medicines in people with Learning Disability.

This process begins on 17 July 2015. We have called an urgent action summit to bring together carers and family representatives, professionals, improvement experts and other key interested parties to agree the steps that need to be taken to reduce the inappropriate use of these medicines and improve this aspect of care in people with learning disabilities who are some of the most vulnerable people in our society. We will issue regular updates on this work and call upon your support in addressing this serious issue.

NICE guidance (NG11) http://www.nice.org.uk/guidance/NG11 published in May 2015, offers guidance on appropriate alternative strategies and interventions.

We have published guidance for those patients and their families and/or carers who may be worried about the medicines they or their loved one is receiving which can be found here.

Yours faithfully

Dominic J Slowie

Dr Dominic Slowie
National Clinical Director for Learning Disability

Dr Keith Ridge CBE
Chief Pharmaceutical Officer

This letter is supported by the following organisations:

Royal College of Nursing

RC PSYCH
ROYAL COLLEGE OF PSYCHIATRISTS

ROYAL PHARMACEUTICAL SOCIETY

Brief guide: psychoactive medicines (LD)

Context

This brief guide is intended to help inspection teams assess whether a provider is adequately managing the use of psychoactive medications in caring for a person with learning disabilities.

A psychoactive medicine, or psychotropic substance, is a chemical substance that alters brain function, resulting in temporary changes in perception, mood, consciousness and behaviour. They include groups of medicines such as antidepressants, antipsychotics, anti-epileptics, mood stabilisers (including sodium valproate and carbamazepine), anxiolytics (benzodiazepines), and central nervous system stimulants.

Evidence required

1. Interview staff, examine care records, policies and procedures, and observe care, checking that staff have:
    a. Considered whether psychoactive medicines were absolutely required, and if so, have combined their use with alternative therapies or behavioural support methods, such as positive behaviour support[1].
    b. Ensured each prescribed medicine addresses the individual's symptoms.
    c. Provided justification for the choice of medicine, with evidence such as a list of symptoms, including risk behaviours when unwell, past psychiatric history, including previous diagnoses, results of psychometric tests and mental status examination assessments, and functional behaviour analyses, as part of a positive behaviour support plan.
    d. Considered the benefits and risks of both having and not having the treatment plan, including potential side effects, any monitoring actions required and physical health issues which may interact with the medicines. Staff should be able to describe Neuroleptic Malignant Syndrome and actions they would take if there were concerns.
    e. Followed General Medical Council (GMC) guidelines on the unlicensed use of prescribed medicines. On its own, challenging behaviour is not a valid indication.
    f. Reviewed people's medicines regularly according to their risk. Newly prescribed medicines should be reviewed more frequently. Reviews should include relevant blood tests or health checks.
    g. Followed the Royal College of Psychiatrists' (RCPsych) guidelines by recording an adequate explanation of any polypharmacy or high dosages.
    h. Sought consent from the person, or consulted with others, such as multidisciplinary team members and carers/family members to make a decision in their best interests (views of those consulted should be documented).
2. Request and review records of regular and effective audits of the use of psychoactive medicines, including evidence of participation in the Prescribing Observatory for Mental Health[2].

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[1] NICE guideline - Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges (May 2015)

[2] Audit topic 9: Use of antipsychotic medicine in people with Learning Disabilities, RCPsych

3. Request evidence from the provider that they monitor and report at least annually on:
    a. the number of people on psychoactive medicines
    b. the number of medicine-related incidents
    c. the number of rapid tranquilisations
    d. the attainment of specific objectives identified in medicine care plans.
4. Request and review records that staff have attended annual training and other activities which maintain staff skills in prescribing and managing psychoactive medicines.

Reporting

1. In the **'track record on safety'** section of **'safe'** comment on the number of medicine-related incidents and rapid tranquilisations.
2. In the **'assessing and managing risk to patients and staff'** section of **'safe'** comment on the extent to which staff make individual patient assessments and management plans that demonstrate good medicines management.
3. In the **'best practice in treatment and care'** section of **'effective'** comment on whether staff manage psychoactive medicines and the provider audits that management against GMC and RCPsych guidelines.
4. In the **'skilled staff to deliver care'** section of **'effective'** comment on whether the provider supports staff to effectively manage psychoactive medicines.
5. In the **'good governance'** section of **'well-led'** comment on whether the provider monitors the attainment of specific objectives identified in psychoactive medicine care plans, such as changes in people's abilities and health.

Policy position

There is limited evidence that psychoactive medicines are effective for people with learning disabilities and behaviours that can challenge. In order to keep people safe and to improve outcomes, it is important that staff prescribe psychoactive medicines safely and in conjunction with a psycho-social intervention such as positive behaviour support to support discontinuation of medication.

A clear rationale for prescribing psychoactive medicines should be recorded in the patient's clinical notes. This should be completed by an adequately trained, supervised specialist, such as a psychiatrist. The notes should also include evidence that staff have exhausted non-pharmacological interventions, a description of what improvement is expected, and a plan for monitoring side effects. There should be a clear link between treatment and evidence of proposed diagnosis. See Appendix 1 for references to more detailed guidance.

Link to regulations

- **Regulation 9** when staff do not appropriately and effectively consider individuals' needs when implementing psychoactive medicine care plans.
- **Regulation 12** when staff have not effectively assessed or managed the safety of the psychoactive medicine.
- **Regulation 13** when staff do not take reasonable steps to use the least-restrictive strategies before considering the use of psychoactive medicine.
- **Regulation 17** when the provider does not effectively audit and monitor the number of incidents or other patient outcomes.
- **Regulation 18** when staff are not suitably competent or skilled in management of psychoactive medicines or supervised by more experienced people.

Appendix 1

Further information

For more detailed information, please see the 2013 and 2014 Learning Disability Census reports[3], the General Medical Council's guidance *Good practice in prescribing and managing medicines and devices* (2013[4]) and the Royal College of Psychiatrists guidance on the use of unlicensed medication (2007[5], under review) and leaflet on anti-psychotics (2015[6]), anti-depressants (2015[7]), and benzodiazepines (2013[8]).

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[3] Health and Social Care Information Centre, *Learning Disability Census.* http://www.hscic.gov.uk/article/6468/Reports-from-the-Learning-Disability-Census-collections

[4] General Medical Council (2013). *Good practice in prescribing and managing medicines and devices*. http://www.gmc-uk.org/guidance/ethical_guidance/14316.asp

[5] Royal College of Psychiatrists (January 2014). *CR142. Use of licensed medicines for unlicensed applications in psychiatric practice.* http://www.rcpsych.ac.uk/usefulresources/publications/collegereports/cr/cr142.aspx

[6] Royal College of Psychiatrists (January 2014). *Anti-psychotics.* http://www.rcpsych.ac.uk/healthadvice/treatmentswellbeing/antipsychoticmedication.aspx

[7] Royal College of Psychiatrists (February 2015). *Anti-depressants.* http://www.rcpsych.ac.uk/healthadvice/treatmentswellbeing/antidepressants.aspx

[8] Royal College of Psychiatrists (July 2013). *Benzodiazepines.* http://www.rcpsych.ac.uk/healthadvice/treatmentswellbeing/benzodiazepines.aspx

Roll out of the Learning Disabilities Mortality Review Programme (LeDeR)
Important information for General Practitioners

The purpose of this communication is to advise you about the LeDeR programme and how you might be asked to participate in it, together with the basis by which patient identifiable information can be shared with the review team. Your support in this service improvement initiative is key.

Please read and cascade this information to appropriate staff within your Practice for their information and action.

The LeDeR programme has been commissioned by NHS England to support local areas in England to review the deaths of people with a learning disability to:

- Identify common themes and learning points
- Provide support to local areas in their development of action plans to take forward the lessons learned

There are two specific ways that GPs and Primary Care Teams may be involved in the LeDeR Programme:

I. One is with regard to notifying the death of **any** of their patients with a learning disability

II. The other is to **input** into a review into the circumstances leading to the death, of those aged 4-74 years. This may involve sharing information about a patient who has died or participating in a multi-agency review where knowledge and perspectives in primary care will be of significant importance.

Learning Disability registers in General Practice indicate a population prevalence of 0.3-1%. Whilst we know that this is lower than the suspected population prevalence of learning disability, the anticipation is that a typical General Practice of circa 6000 patients will have a relatively small number of patients with known learning disability. As such we anticipate the workload at practice level for information sharing or participation in the review of a death of a patient with learning disability will be minimal.

Important: The LeDeR programme has established pilot sites in each region of England. Once each pilot site has shared their learning, the programme is being rolled out across the rest of that region. **Notification of deaths is currently required in NHS England North; Wessex; Leicestershire, Leicester City and Rutland.**

Legal basis for sharing patient identifiable information

The LeDeR programme is part of a suite of programmes previously known as confidential enquiries. It has approval from the Secretary of State under section 251 of the NHS Act 2006 to process patient identifiable information without the patient's consent.

The GMC Confidentiality Guidance (paragraphs 71b and 71c) advises that doctors should disclose relevant information about a patient who has died where disclosure is authorised under section 251 of the NHS Act 2006.

The LeDeR programme strives to ensure that reviews of deaths lead to learning which will result in improved health and social care services for people with learning disabilities. It is not an investigation nor is it aimed at holding any individual or organisation to account. If individuals and organisations are to be able to learn lessons from the past it is important that the reviews are trusted and safe experiences that encourage honesty, transparency and the sharing of information in order to obtain maximum benefit from them.

For FAQs and further information about the programme, please contact the LeDeR team at:

E: leder-team@bristol.ac.uk **T:** 0117 331 0686 **W:** www.bristol.ac.uk/sps/leder

Working together for adults with complex needs

Lynzee McShea – Senior Clinical Scientist (Audiology)

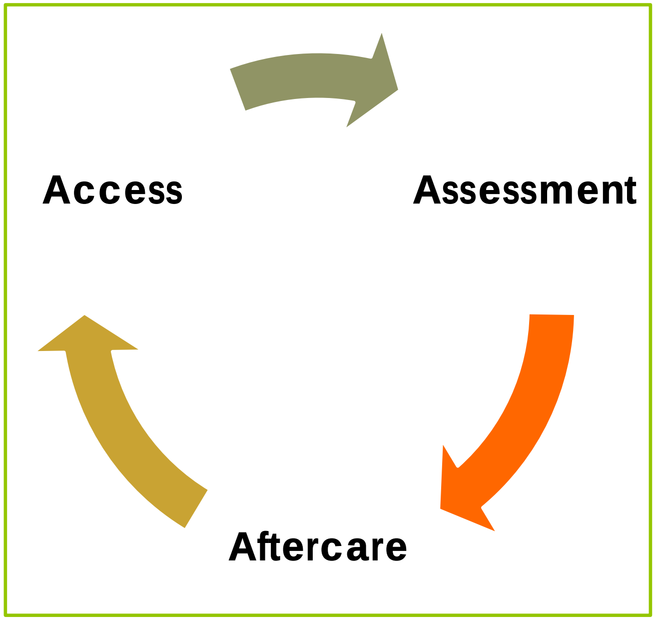
Emma McNeill – Consultant ENT Surgeon

City Hospitals Sunderland

The issue at hand

- People with learning disabilities are at a higher risk of hearing loss
- At least 40% will have a hearing loss
- Significant unmet need, on a local, national and international scale
- ~ 6000 PWLD in Sunderland
- Ideally aware of 2,400 individuals
- The reality < 1%

Range of barriers – 3A's



Our service in Sunderland

We are an award winning service

We are unique in the region

Audiology team wins major UK award

Congratulations to Lynzee McShea, senior clinical scientist in audiology and Chris Corkish, senior lecturer who have won a major UK award for their work in detecting and managing hearing loss in people with learning disabilities.

They and their team created the idea of the 3As, Access, Assessment, Aftercare, which has enriched the lives of many people with learning disabilities, some of whom are now able to speak for the first time. The 3As, say the judges, can be put into action in any service, not only audiology.

- We have had a dedicated clinic for people with complex needs in Audiology since 2008
- We make a range of reasonable adjustments across our pathway
- Even people with severe or profound LD can have their hearing assessed
- We are passionate about improving our service

Carer research

- Our pathway relies on caregivers
- Aim to improve Access and Aftercare

Stage 1

- 20 paid caregivers in Sunderland
- Negative perception of hearing aids
- Were doubtful of Audiology's ability to complete an assessment
- Caregivers made suggestions on training content and format

Stage 2

- Training designed and piloted with over 50 caregivers
- Estimated prevalence doubled from 23 to 46%
- Pledges made following training
- Within 6 months, 96% were completed
- Every service user identified had a hearing need

Before

"I don't know anything about hearing"

"None of the people we support would be able to go through a hearing test"

After

"We were trained to think about it more, its not just their learning disability, they aren't just ignoring you, it's not just them"

"I feel more knowledgeable and have more understanding. I have been here 5 years and it has never crossed my mind before"

Research in primary care

- Completed earlier this year
- Visited 9 practices in Sunderland
- All provided annual health checks for PWLD

- Prevalence data was available in some of these practices
- Ranged from 0 – 14%
- Are health checks an effective tool to detect hearing loss?

Some assumptions were being made:

  - That hearing loss would already have been identified elsewhere
  - That it would not be possible to test the hearing of someone with complex needs
  - That PWLD would not benefit from hearing aids

Comment from a caregiver:

“Before I would have thought the GP would just turn us away, but now it’s better ‘cos we have information to go with”

Comments from primary care professionals:

“I can’t recall a person with learning disabilities ever having hearing problems”

“Now we know that you can actually test someone who may not react, even though they can hear it, gives us incentive to pursue it. We know there is a way now”

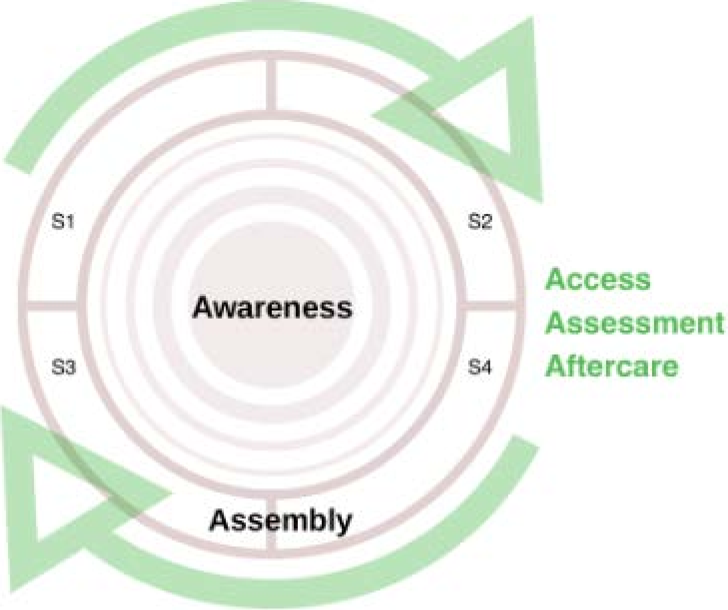
Action points from research

	Prevalence estimate	Actual prevalence
Paid caregivers	25%	7%
Primary care professionals	20%	0-14%

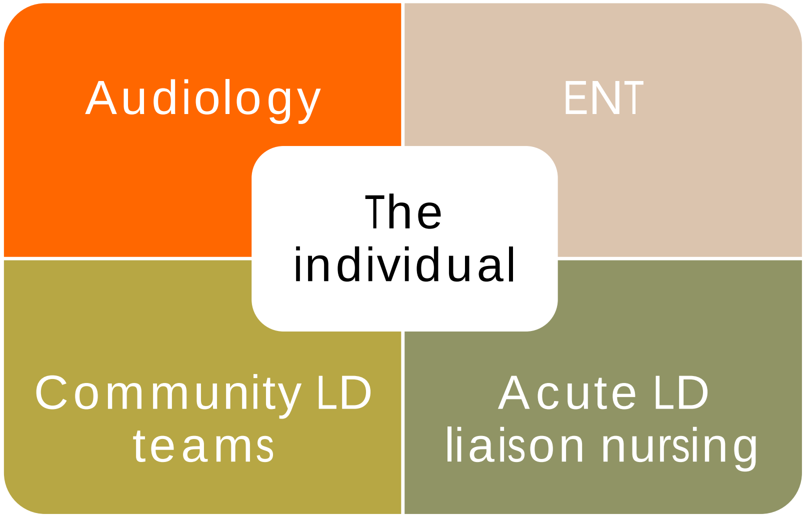
Suggestions made:

- Information sharing at TITO
- Publicise services available
  - Now available on C&B
- Education around correct referral routes
- Information sharing via local carer's centre
- Greater team working

The 5As model



The complex needs MDT



Audiology

ENT

The individual

Community LD teams

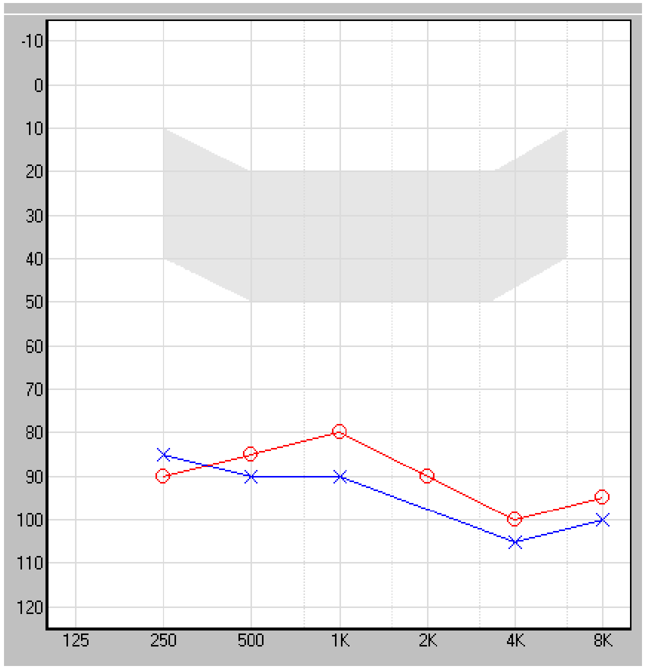
Acute LD liaison nursing

- We needed to improve awareness and assemble key groups
- Increase our visibility in the community
- We began in January 2015
- We now have excellent links with community teams
- Keen to increase membership further
- Operational and strategic focus

“People with LD can’t benefit from hearing aids”

David’s story then

- Moderate LD and autism
- Non verbal
- Challenging behaviours
- No concerns regarding hearing
- “David wouldn’t wear hearing aids”



David’s story now

- He loves his hearing aids
- He has started to speak
- Carers find it easier to support him
- He is able to make his own choices more
- His challenging behaviour has stopped
- His may have been misdiagnosed with autism

“People with LD can’t be assessed”

Sarah’s caregivers were told by a private Audiology provider that Sarah was untestable, but we successfully diagnosed her with a moderate hearing loss and now enjoys using hearing aids to listen to music on her iPad

Jack was identified by his community LD nurse as being at risk of hearing loss. At his appointment he reported some dizziness. ENT found postural hypotension

Kieran was referred to Audiology via his community speech and language therapist. He was found to have middle ear fluid and a history of chronic infections, always treated in primary care. Audiology referred to ENT. Kieran had an assessment under GA, he was found to have a moderate hearing loss and a Right cholesteatoma, which requires further surgery and long term care.

Summary and next steps

- There is still significant undetected hearing loss in this patient group in Sunderland
- We have a well established, “reasonably adjusted” service
- Anyone can have their hearing tested
- PWLD can benefit from hearing aids

- There is lots more work still to do
- We would like to be more visible in the community
  - Links with Sunderland’s role as a vanguard site
  - Possible CQUIN target?
- We would like a primary care representative in our MDT

Dental/Orthodontic Services Referral Form Appendix 17

Please complete all the relevant information

Referral to:	Community Service ☐	Orthodontics ☐
		Orthodontic Contract Yes ☐ No ☐

Referred by: Designation:		Address / stamp:
Signature		
Date:	☎:	

Patient Details

Name:	Date of birth:	Sex: M F
Contact address: Postcode:		
Primary ☎:	Mobile ☎:	
Interpreter needed? Yes ☐ No ☐ Language:		

Significant Medical History or Additional Health Needs

Special Needs: Medical ☐ Physical ☐ Learning disability ☐ Mental Health issues ☐ Extreme Anxiety/phobia ☐ Other ☐	Please give details: **Doctor's name** **Address** ☎:
Wheel chair user? yes ☐ no ☐	
Domiciliary visits? yes ☐ no ☐	

PTO

Dental/Orthodontic History and Attempted Treatment

Reason for Referral

Treatment Required			
Extraction	**Conservation**	**Periodontal Care**	
Proposed Treatment Under	GA ☐	RA ☐	IV ☐

Please note: *Decision on appropriate method of anxiety control will only be made following consultation*

To conform with the IRMER guidelines please send all OPGs and other relevant radiographs with this referral.				
Radiographs sent? If no please state reason why?	**Yes**	☐	**No**	☐ **REASON**
OPG sent?		☐		
Other sent?		☐		

Failure to provide radiographs with this form may delay the time it takes for initial assessment by the Service.

Any Relevant Additional Information

Please return to:
Dental dep
Referrals Coordinator
The Galleries Health Centre
Washington Way
Washington
Tyne & Wear
NE38 7NQ
Tel: 0191 502 6754
Fax: 0191 502 6762

For Office Use only:
Received:
Appointment Date: Time:=

THE FIVE YEAR FORWARD VIEW FO MENTAL HEALTH

A report from the independent Mental Health Taskforce to the NHS in England
February 2016

CONTENTS

EXECUTIVE SUMMARY

THE CURRENT STATE OF MENTAL HEALTH

“The NHS needs a far more proactive and preventative approach to reduce the long term impact for people experiencing mental health problems and for their families, and to reduce costs for the NHS and emergency services”.

Mental health problems are widespread, at times disabling, yet often hidden. People who would go to their GP with chest pains will suffer depression or anxiety in silence. **One in four adults** experiences at least one diagnosable mental health problem in any given year. People in all walks of life can be affected and at any point in their lives, including new mothers, children, teenagers, adults and older people. Mental health problems represent the largest single cause of disability in the UK. The cost to the economy is estimated at £105 billion a year – roughly the cost of the entire NHS.

POLICY CONTEXT

There has been a **transformation in mental health** over the last 50 years. Advances in care, the development of anti-psychotic and mood stabilising drugs, and greater emphasis on human rights led to the growth of community based mental health services. In the 1990s, the Care Programme Approach was developed to provide more intensive support to people with severe and enduring mental illness. There was a new emphasis on promoting public mental health and developing services for children and homeless people. In 1999, the National Service Framework for Mental Health was launched to establish a comprehensive evidence based service. This was followed by the NHS Plan in 2000 which set targets and provided funding to make the Framework a reality. A National Service Framework for Children, Young People and Maternity Services was then launched in 2004.

In 2011, the Coalition government published a **mental health strategy** setting six objectives, including improvement in the outcomes, physical health and experience of care of people with mental health problems, and a reduction in avoidable harm and stigma. The strategy was widely welcomed. However, despite these initiatives, challenges with system wide implementation coupled with an increase in people using mental health services has led to inadequate provision and worsening outcomes in recent years, including a rise in the number of people taking their own lives.

Yet, over the last five years, public attitudes towards mental health have improved, in part due to the Time to Change campaign. In turn, this increased awareness has heightened understanding of an urgent need to act on improving the experiences of people with mental health problems, both within and beyond the NHS. There is now a need to **re-energise and improve mental health care across the NHS** to meet increased demand and improve outcomes.

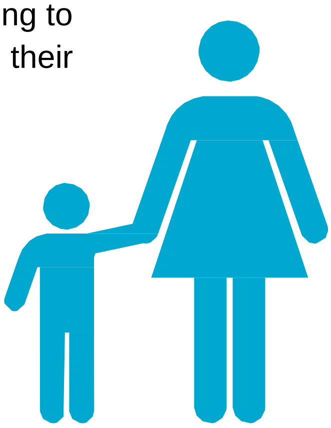
In this context, NHS England and the Department of Health **published Future in Mind** in 2015, which articulated a clear consensus about the way in which we can make it easier for children and young people to access high quality mental health care when they need it. This strategy builds on these strong foundations.

Mental health has not had the priority awarded to physical health, has been short of qualified staff and has been deprived of funds. We must provide equal status to mental and physical health, equal status to mental health staff and equal funding for mental health services as part of a triple approach to improve mental health care – a fresh mindset for mental health within the NHS and beyond.

MENTAL HEALTH PROBLEMS IN THE POPULATION

Half of all mental health problems have been established by the age of 14, rising to 75 per cent by age 24. **One in ten children** aged 5 – 16 has a diagnosable problem such as conduct disorder (6 per cent), anxiety disorder (3 per cent), attention deficit hyperactivity disorder (ADHD) (2 per cent) or depression (2 per cent). Children from low income families are at highest risk, three times that of those from the highest. Those with conduct disorder - persistent, disobedient, disruptive and aggressive behaviour - are twice as likely to leave school without any qualifications, three times more likely to become a teenage parent, four times more likely to become dependent on drugs and 20 times more likely to end up in prison. Yet most children and young people get no support. Even for those that do the average wait for routine appointments for psychological therapy was 32 weeks in 2015/16. A small group need inpatient services but, owing to inequity in provision, they may be sent anywhere in the country, requiring their families to travel long distances.

1 IN 10 CHILDREN AGED 5-16
YEARS HAVE A DIAGNOSABLE
MENTAL HEALTH PROBLEM



One in five mothers suffers from depression, anxiety or in some cases psychosis during pregnancy or in the first year after childbirth. Suicide is the second leading cause of maternal death, after cardiovascular disease. Mental health problems not only affect the health of mothers but can also have long-standing effects on children's emotional, social and cognitive development. Costs of perinatal mental ill health are estimated at £8.1 billion for each annual birth cohort, or almost £10,000 per birth. Yet fewer than 15 per cent of localities provide effective specialist community perinatal services for women with severe or complex conditions, and more than 40 per cent provide no service at all.

Physical and mental health are closely linked – **people with severe and prolonged mental illness are at risk of dying on average 15 to 20 years earlier than other people** – one of the greatest health inequalities in England. Two thirds of these deaths are from avoidable physical illnesses, including heart disease and cancer, many caused by smoking. There is also a lack of access to physical healthcare for people with mental health problems – less than a third of people with schizophrenia in hospital received the recommended assessment of cardiovascular risk in the previous 12 months.

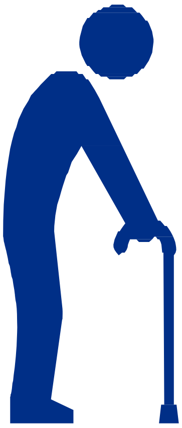
In addition, **people with long term physical illnesses suffer more complications if they also develop mental health problems,** increasing the cost of care by an average of 45 per cent. Yet much of the time this goes unaddressed. There is good evidence that dedicated mental health provision as part of an integrated service can substantially reduce these poor outcomes. For example, in the case of Type 2 diabetes, £1.8 billion of additional costs can be attributed to poor mental health. Yet fewer than 15 per cent of people with diabetes have access to psychological support. Pilot schemes show providing such support improves health and cuts costs by 25 per cent.

Stable employment and housing are both factors contributing to someone being able to maintain good mental health and are important outcomes for their recovery if they have developed a mental health problem. Between 60–70 per cent of people with common mental health problems are in work, yet few employees have access to specialist occupational health services. For people being supported by secondary mental health services, there is a 65 per cent employment gap compared with the general population. People with mental health problems are also often overrepresented in high-turnover, low-pay and often part-time or temporary work. Common mental health problems are over twice as high among people who are homeless compared with the general population, and psychosis is up to 15 times as high. Children living in poor housing have increased chances of experiencing stress, anxiety and depression.

Only **half of veterans of the armed forces** experiencing mental health problems like Post Traumatic Stress Disorder seek help from the NHS and those that do are rarely referred to the right specialist care. NHS England is currently consulting on the future of mental health support for this group and it is essential that more is done to ensure their needs are identified early and they are supported to access specialist care swiftly.

One in five older people living in the community and 40 per cent of older people living in care homes are affected by depression. Diagnosing depressive symptoms can be difficult, and we know that some clinicians believe treatment for depression is less effective in older people, despite evidence to the contrary.

40 PER CENT OF OLDER PEOPLE LIVING IN CARE HOMES ARE AFFECTED BY DEPRESSION



People in **marginalised groups** are at greater risk, including black, Asian and minority ethnic (BAME) people, lesbian, gay, bisexual and transgender people, disabled people, and people who have had contact with the criminal justice system, among others. BAME households are more likely to live in poorer or over-crowded conditions, increasing the risks of developing mental health problems.

People of all ages who have experienced traumatic events, poor housing or homelessness, or who have multiple needs such as a learning disability or autism are also at higher risk.

As many as **nine out of ten people in prison** have a mental health, drug or alcohol problem.

Suicide is rising, after many years of decline. Suicide rates in England have increased steadily in recent years, peaking at 4,882 deaths in 2014. The rise is most marked amongst middle aged men. Suicide is now the leading cause of death for men aged 15–49. Men are three times more likely than women to take their own lives - they accounted for four out of five suicides in 2013. A quarter of people who took their own life had been in contact with a health professional, usually their GP, in the last week before they died. Most were in contact within a month before their death.

More than a quarter (28 per cent) of suicides were amongst people who had been in contact with mental health services within 12 months before their death, amounting to almost 14,000 people in the ten years from 2003-2013. However, suicides amongst inpatients in mental hospitals have significantly declined over the same period, as a result of better safety precautions.

CURRENT EXPERIENCES OF MENTAL HEALTH CARE

Nearly two million adults were in contact with **specialist mental health and learning disability services** at some point in 2014/15 – though we know little about the quality of their care and there remains extensive unmet need for mental health care. Three quarters of people with mental health problems receive no support at all. Among those who are helped, too few have access to the full range of interventions recommended by National Institute for Health and Care Excellence (NICE), including properly prescribed medication and psychological therapy.

Nine out of ten adults with mental health problems are supported in primary care. There has been a significant expansion in access to psychological therapies, following the introduction of the national IAPT programme (Improving Access to Psychological Therapies). However, there is considerable variation in services, with a waiting time of just over six days in the best performing areas and 124 days in the worst performing areas in 2014-15.

Of those adults with more **severe mental health problems** 90 per cent are supported by community services. However, within these services there are very long waits for some of the key interventions recommended by NICE, such as psychological therapy, and many people never have access to these interventions. One-quarter of people using secondary mental health services do not know who is responsible for coordinating their care, and the same number have not agreed what care they would receive with a clinician. Almost one-fifth of people with care coordinated through the Care Programme Approach (for people with more severe or complex needs) have not had a formal meeting to review their care in the previous 12 months.

NINE OUT OF TEN ADULTS WITH MENTAL HEALTH PROBLEMS ARE SUPPORTED IN PRIMARY CARE

In its recent review of **crisis care**, the Care Quality Commission found that only 14 per cent of adults surveyed felt they were provided with the right response when in crisis, and that only around half of community teams were able to offer an adequate 24/7 crisis service. Only a minority of hospital Accident & Emergency (A&E) departments has 24/7 cover from a liaison mental health service, even though the peak hours for mental health crisis presentations to A&E are between 11pm and 7am. Too often, people in mental health crisis are still accessing mental health care via contact with the police. The inquiry found that while adults were seen promptly where liaison mental health services were available in an A&E department and there were clear pathways through to community services, those aged under 16 were referred directly to children and young people's services but seen only when services were open during office hours. This could involve waiting a full weekend and lead to a significant variation in the quality of care on the basis of someone's age.

Admissions to **inpatient care** have remained stable for the past three years for adults but the severity of need and the number of people being detained under the Mental Health Act continues to increase, suggesting opportunities to intervene earlier are being missed. Men of African and Caribbean heritage are up to 6.6 times more likely to be admitted as inpatients or detained under the Mental Health Act, indicating a systemic failure to provide effective crisis care for these groups.

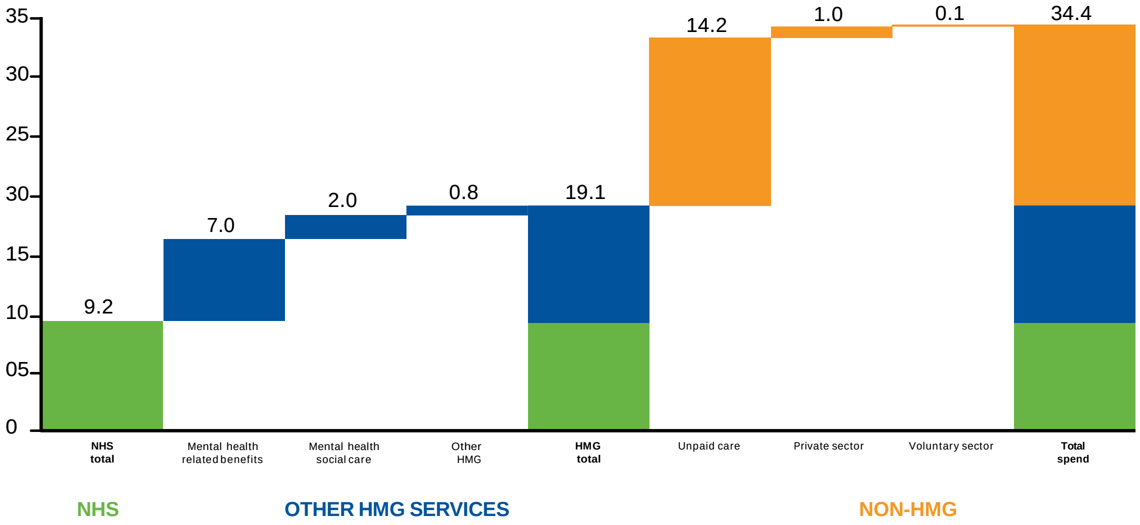
The number of adult inpatient psychiatric beds reduced by 39 per cent overall in the years between 1998 and 2012. For children and young people, average admissions per provider increased from 94 in 2013/14 to 106 in 2014/15. **Bed occupancy** has risen for the fourth consecutive year to 94 per cent. Many acute wards are not always safe, therapeutic or conducive to recovery. Pressure on beds has been exacerbated by a lack of early intervention and crisis care, and the resulting shortage leads to people being transferred long distances **outside of their area**.

Mental health accounts for 23 per cent of NHS activity but NHS **spending** on secondary mental health services is equivalent to just half of this. Years of low prioritisation have led to Clinical Commissioning Groups (CCGs) underinvesting in mental health services relative to physical health services but the degree of the disparity has largely been obscured by the way spending on mental health conditions is grouped together and reported, unlike spend on physical health care, which is disaggregated by specific conditions. Spending per capita across CCGs varies almost two-fold in relation to underlying need.

£34 BILLION **EACH YEAR SPENT ON MENTAL HEALTH**

Poor mental health carries an **economic and social cost of £105 billion a year** in England. Analysis commissioned by NHS England found that the national cost of dedicated mental health support and services across government departments in England totals £34 billion each year, excluding dementia and substance use [1].

Total cost of mental health support and services in England 2013/14 (£bn)



Note: this analysis aims to capture direct spend on services provided to support those with mental ill-health; it does not factor in second-order costs in other public services or wider society Source: Programme Budgeting, Departments' finance data, HSCIC, DWP spend on benefits

£19 billion of this is made up of government spend, though there is little or no national data available for how up to 67 per cent of mental health funding is used at a local level. Most of the remainder (£14bn) is for the support provided by unpaid carers, plus a relatively small share that is funded through the private and voluntary sectors.

Given chronic underinvestment in mental health care across the NHS in recent years, efficiencies made through achieving better value for money should be **re-invested to meet the significant unmet mental health needs** of people of all ages across England, and to improve their experiences and outcomes.

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[1] NHS England internal analysis

WHAT NEEDS TO HAPPEN - A FRESH MINDSET

“We should have fewer cases where people are unable to get physical care due to mental health problems affecting engagement and attendance (and vice versa). And we need provision of mental health support in physical health care settings - especially primary care.”

People told us that their mental health needs should be treated with equal importance to their physical health needs, whatever NHS service they are using – this is a fundamental principle of the Taskforce recommendations.

All too often people living with mental health problems still experience stigma and discrimination, many people struggle to get the right help at the right time and evidence-based care is significantly underfunded. The human cost is unacceptable and the financial cost to government and society is unsustainable.

Leaders across the system must take decisive steps to break down barriers in the way services are provided to reshape how care is delivered, increase access to the right care at the right time, drive down variations in the quality of care on offer, and improve outcomes.

Our ambition is to deliver rapid improvements in outcomes by 2020//21 through ensuring that 1 million more people with mental health problems are accessing high quality care. In the context of a challenging Spending Review, **we have identified the need to invest an additional £1 billion in 2020/21**, which will generate significant savings. It builds on the £280 million investment each year already committed to drive improvements in children and young people’s mental health, and perinatal care.

PRIORITY ACTIONS FOR THE NHS BY 2020/21

1. A 7 day NHS – right care, right time, right quality

“If you feel unwell in the evening, during the night or at the weekends and bank holidays there is no choice but to go to A&E. There’s no support out there during these times. It’s crucial that this is changed for the benefit of service users, their families and carers.”

People facing a crisis should have access to mental health care **7 days a week** and 24 hours a day in the same way that they are able to get access to urgent physical health care. Getting the right care in the right place at the right time is vital. Failure to provide care early on means that the acute end of mental health care is under immense pressure. Better access to support was one of the top priorities identified by people in our engagement work. Early intervention services provided by dedicated teams are highly effective in improving outcomes and reducing costs.

The Care Quality Commission (CQC) found that just half of Community Mental Health Teams (CMHTs) are able to offer a 24/7 crisis service today. By 2020/21, NHS England should ensure that a 24/7 community-based mental health crisis response is available in all areas across England and that services are adequately resourced to offer intensive home treatment as an alternative to acute inpatient admission. For adults, NHS England should invest to expand Crisis Resolution and Home Treatment Teams (CRHTTs); for children and young people, an equivalent model of care should be developed within this expansion programme. **Out of area placements for acute care should be reduced and eliminated as quickly as possible.**

Good liaison mental health care is also needed in acute hospitals across the country, providing a 24/7 urgent and emergency mental health response for people attending A&E or admitted as inpatients to acute hospitals. Only a minority of A&E departments have 24/7 liaison mental health services that reach minimum quality standards, even though peak hours for people presenting to A&E with mental health crises are 11pm-7am. By 2020/21 no acute hospital should be without all-age mental health liaison services in emergency departments and inpatient wards, and at least 50 per cent of acute hospitals should be meeting the ‘core 24’ service standard as a minimum.

People experiencing a first episode of psychosis should have access to a NICE-approved care package within 2 weeks of referral. Delay in providing care can lead to poorer clinical and social outcomes. The NHS should ensure that by April 2016 more than 50 per cent of this group have access to Early Intervention in Psychosis services, rising to at least 60 per cent by 2020/21.

People want care in the least restrictive setting that is appropriate to meet their individual needs, at any age, and is close to home. People living with severe mental health problems, such as schizophrenia or personality disorder, should not be held in restrictive settings for longer than they need to be. **The NHS should expand proven community-based services for people of all ages with severe mental health problems who need support to live safely as close to home as possible.**

More ‘step-down’ help should be provided from secure care, such as residential rehabilitation, supported housing and forensic or assertive outreach teams. By April 2017, population-based budgets should be in place for those CCGs who wish to commission specialised services for people of all ages, in partnership with local government and national specialised commissioners. The Taskforce welcomes the invitation set out in NHS England Planning Guidance 2016/17 – 2020/21 for providers of secondary mental health services to manage budgets for tertiary (specialised) services, to reduce fragmented commissioning and improve full community and inpatient care pathways.

A 7 DAY CRISIS RESPONSE SERVICE WILL HELP SAVE LIVES

7 DAY

Improving the 7 day crisis response service across the NHS will help save lives as part of a major drive to **reduce suicide by 10 per cent by 2020/21.** Every area must develop a multi-agency suicide prevention plan that demonstrates how they will implement interventions targeting high-risk locations and supporting high-risk groups within their population.

Some people experience unacceptably poor access to or quality of care. There has been no improvement in race inequalities relating to mental health care since the end of the 5-year Delivering Race Equality programme in 2010. **Inequalities in access** to early intervention and crisis care, rates of detentions under the Mental Health Act 1983 and lengths of stay in secure services persist.

National and local commissioners must show leadership in tackling unwarranted variations in care. The Department of Health should address race equality as a priority and appoint a new equalities champion to drive change.

Measures must be taken to ensure all deaths across NHS-funded inpatient mental health services are properly investigated, and learned from to improve services and prevent repeat events. By April 2017, the Department of Health should establish an independent system for the assurance of the quality of investigations of all deaths in inpatient mental health services and to ensure a national approach to applying learning to service improvement.

2. An integrated mental and physical health approach

"Making physical and mental health care equally important means that someone with a disability or health problem won't just have that treated, they will also be offered advice and help to ensure their recovery is as smooth as possible, or in the case of physical illness a person cannot recover from, more should be done for their mental wellbeing as this is a huge part of learning to cope or manage a physical illness."

People told us that mental health support should be made easily available across the NHS - for mums to be, children, young adults visiting their GP, people worried about stress at work, older people with long-term physical conditions and people receiving care for cancer or diabetes.

People with existing mental health problems told us that services should be integrated - for example, physical health checks and smoking cessation programmes should be made available for everyone with a severe mental illness.

The impact of mental health problems experienced by women in pregnancy and during the first year following the birth of their child can be devastating for both mother and baby, as well as their families. **By 2020/21, NHS England should support at least 30,000 more women each year to access evidence-based specialist mental health care during the perinatal period.** This should include access to psychological therapies and the right range of specialist community or inpatient care so that comprehensive, high-quality services are in place across England.

By 2020/21, at least 280,000 people living with severe mental health problems should have their physical health needs met. They should be offered screening and secondary prevention reflecting their higher risk of poor physical health. This will reduce the health inequalities gap. We know there is low take up of information, tests and interventions relating to physical activity, smoking, alcohol problems, obesity, diabetes, heart disease and cancer. In England there are over 490,000 people with severe mental illness registered with a GP. The proportion receiving an annual physical health check ranges from 62 per cent to 82 per cent (this data does not include any information about how many people are being supported to access evidence based interventions as a result of these checks). People with a long standing mental health problem are twice as likely to smoke, with the highest rates among people with psychosis or bipolar disorder. Current incentive schemes for GPs to encourage monitoring of physical health should continue and extra efforts should be made to reduce smoking - one of the most significant causes of poorer physical health for this group. Mental health inpatient services should be smoke free by 2018.

The provision of psychological therapies for people with common mental health problems has expanded hugely in recent years. But it is still meeting only 15 per cent of need for adults. NHS England should **increase access to evidence-based psychological therapies to reach 25 per cent of need so that at least 600,000 more adults with anxiety and depression can access care (and 350,000 complete treatment) each year by 2020/21.** There should be a focus on helping people who are living with long-term physical health conditions or who are unemployed. There must also be investment to increase access to psychological therapies for people with psychosis, bipolar disorder and personality disorder.

PEOPLE WITH A LONG STANDING MENTAL HEALTH PROBLEM ARE TWICE AS LIKELY TO SMOKE

3. Promoting good mental health and preventing poor mental health– helping people lead better lives as equal citizens

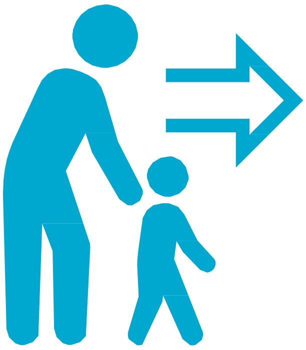
“If I’d had the help in my teens that I finally got in my thirties, I wouldn’t have lost my twenties.”

Prevention matters - it’s the only way that lasting change can be achieved. Helping people lead fulfilled, productive lives is not the remit of the NHS alone. It involves good parenting and school support during the early years, decent housing, good work, supportive communities and the opportunity to forge satisfying relationships. These span across national and local government, so the Taskforce has a set of recommendations to build on the Prime Minister’s commitment to a “mental health revolution.”

Prevention at key moments in life

Children and young people are a priority group for mental health promotion and prevention, and we are calling for the Future in Mind recommendations to be implemented in full. Early intervention and quick access to good quality care is vital – especially for children and young people. Waiting times should be substantially reduced, significant inequalities in access should be addressed and support should be offered while people are waiting for care.

By 2020/21, at least 70,000 more children and young people should have access to high-quality mental health care when they need it. This will require a fundamental change in the way services are commissioned, placing greater emphasis on prevention, early identification and evidence-based care. NHS England should continue to work with partners to fund and implement the whole system approach described in Future in Mind, building capacity and capability across the system so that by 2020/21 we will secure measurable improvements in children and young people’s mental health outcomes. We need to ensure that good quality local transformation plans are put into action, invest in training to ensure that all those working with children and young people can identify mental health problems and know what to do, complete the roll-out of the Children and Young People's Improving Access to Psychological Therapies (CYP IAPT) programme across England by 2018 and develop an access standard for Child and Adolescent Mental Health Services (CAMHS) by the end of 2016/17. This should build on the standard for children and young people with eating disorders announced in July 2015.



BY 2020/21 AT LEAST 70,000 MORE CHILDREN AND YOUNG PEOPLE SHOULD HAVE ACCESS TO **HIGH-QUALITY** MENTAL HEALTH CARE

In addition, some children are particularly vulnerable to developing mental health problems - including those who are looked after or adopted, care leavers, victims of abuse or exploitation, those with disabilities or long term conditions, or who are within the justice system. The Departments of Health and Education should establish an expert group to examine their complex needs and how they should best be met, including through the provision of personalised budgets. The Government should also review the best way to ensure that the significant expansion of parenting programmes announced by the Prime Minister builds on the strong-evidence base that already exists and is integrated with Local Transformation Plans for Children and Young People's mental health services.

The **employment rate for adults** with mental health problems remains unacceptably low: 43 per cent of all people with mental health problems are in employment, compared to 74 per cent of the general population and 65 per cent of people with other health conditions. Of people with 'mental and behavioural disorders' supported by the Work Programme, only 9.5 per cent have been supported into employment, a lower proportion than for some proven programmes. There is a 65 per cent point gap between the employment rates of people being supported by specialist mental health services who have more severe health problems and the general population.

Employment and health form a virtuous circle: suitable work can be good for your health, and good health means that you are more likely to be employed.

By 2020/21, each year up to 29,000 more people living with mental health problems should be supported to find or stay in work through increasing access to psychological therapies for common mental health problems and expanding access to Individual Placement and Support (IPS).

Employment is vital to health and should be recognised as a health outcome. The NHS must play a greater role in supporting people to find or keep a job. Access to psychological support must be expanded to reach at least a quarter of all people who need it. There must be a doubling of access to Individual Placement and Support programmes to reach an extra 30,000 people living with severe mental illness (so that at least 9,000 are in employment), and the new Work and Health Programme should prioritise investment in health-led interventions that are proven to work for people with mental health problems.

JUST 43%
OF PEOPLE WITH MENTAL HEALTH PROBLEMS ARE IN EMPLOYMENT

Creating mentally healthy communities

We heard from many people about the importance of the role of Local Government in the promotion and prevention agenda. Building on the success of local Crisis Care Concordat Plans, we recommend the creation of local Mental Health Prevention Plans, based on high quality evidence.

Housing is critical to the prevention of mental health problems and the promotion of recovery. The Department of Health, the Department of Communities and Local Government, NHS England, HM Treasury and other agencies should work with local authorities to build the evidence base for specialist housing support for vulnerable people with mental health problems and explore the case for using NHS land to make more supported housing available for this group.

In relation to the proposed Housing Benefit cap to Local Housing Allowance levels, the Department of Work and Pensions should use evidence to ensure that the right levels of protection are in place for people with mental health problems who require specialist supported housing. The Ministry of Justice, Home Office, Department of Health, NHS England and Public Health England should work together to **support those in the criminal justice system experiencing mental health problems** by expanding- liaison and diversion schemes nationally, increasing support for Blue Light services, and for the 90 per cent of people in prison with mental health problems, drug or alcohol problems.

Ending the **stigma** around mental ill health is vital. The Department of Health and Public Health England should continue to help local communities build a grass roots social movement to raise awareness of good physical and mental health and support people to seek help when they need it.

Building a better future

"There should be even greater emphasis put on people's experience and how experts-by-experience can be seen as real assets to design and develop services."

The next five years will build the foundations for the next generation.

The UK should be a world leader in the development and application of new **mental health research**. The Department of Health, working with relevant partners, should publish a ten year strategy for mental health research one year from now including a co-ordinated plan for strengthening the research pipeline on identified priorities, and promoting implementation of research evidence.

A **data and transparency revolution** is required to ensure greater consistency in the availability and quality of NHS-funded services across the country.
The information gathered by the NHS should reflect social as well as clinical outcomes – e.g. education, employment and housing **-** that matter to people with mental health problems. This requires better data linkage across the NHS, public health, education and other sectors, with absolute transparency on spending in relation to prevalence, access, experience and outcomes. **By 2020/21, CCGs should be required to publish a range of benchmarking data to provide transparency about mental health spending and performance.**

DELIVERING THIS STRATEGY

“Being both a junior doctor training in psychiatry, and a patient with mental health problems, enables me to experience both sides of the NHS, and I feel this gives me a great advantage and insight. Whilst a lot of the work I experience on both sides is very positive, I am frequently amazed by the heavy workloads of my colleagues and those treating me. And I know that for me, this can in fact contribute to deterioration in my own mental health.”

Mental health services have been chronically underfunded. We know that the presence of poor mental health can drive a 50 per cent increase in costs in physical care. The Taskforce considers it a point of basic parity between physical and mental health that types of care and therapies shown to lead to improved mental health outcomes and found to be cost-effective should be made available to people with mental health problems. Without upfront investment it will not be possible to implement this strategy and deliver much-needed improvements to people’s lives, as well as savings to the public purse.

£1 BILLION

ADDITIONAL INVESTMENT NEEDED

Over the next five years additional funding should allow NHS England to expand access to effective interventions. The priority areas we have identified would require an additional £1 billion investment in 2020/21, which will contribute to plugging critical gaps in the care the NHS is currently unable to provide. Our expectation is that savings and efficiencies generated by improved mental health care e.g. through a strengthened approach to prevention and early intervention, and through new models of care, will be re-invested in mental health services.

To deliver these commitments and realise the associated savings NHS England must be able to target investment and ensure there is sufficient transparency and accountability for putting them into action. Both the current Mandate priorities and those set out in this report should specifically be reflected in the local Sustainability and Transformation plans that areas will need to produce by June 2016, in how those plans are assessed and in the processes for allocating and assuring funds.
We recommend eight principles to underpin reform:

- Decisions must be locally led
- Care must be based on the best available evidence

- Services must be designed in partnership with people who have mental health problems and with carers
- Inequalities must be reduced to ensure all needs are met, across all ages
- Care must be integrated – spanning people's physical, mental and social needs
- Prevention and early intervention must be prioritised
- Care must be safe, effective and personal, and delivered in the least restrictive setting
- The right data must be collected and used to drive and evaluate progress

We make specific recommendations on the need to develop and support the mental health workforce, making it a career option of choice across medicine, social care, the allied health professions and the voluntary sector. We encourage the further development of personalised care, giving people choice in their own care, and the expansion of peer support.

We make a series of fundamental recommendations to hardwire mental health into how care is commissioned, funded, and inspected, across the whole NHS. These should enable mental health to be fully embedded in NHS planning and operations for the duration of the Five Year Forward View.

Co-production with experts-by-experience should also be a standard approach to commissioning and service design, with Arm's Length Bodies (ALBs) leading by example and supporting this practice in local areas. We recommend the creation of a Mental Health Advisory Board reporting to the Five Year Forward View Board, publicly updating on progress against our recommended outcomes. We also encourage the Cabinet Office and Department of Health to put in place cross-government oversight of the wider actions we are recommending the Government should take, in addition to those being led by the NHS.

Conclusion

A summary of our recommendations can be found in the second annex of this report. Delivery of these recommendations is everybody's business - for the NHS, for health and social care professionals, for providers, employers, across government and communities.

But the critical element of success will be to put the individual with their own lived experience of mental health at the heart of each and every decision which is made. We have much to be proud of in the progress that has been made in empowering people to make their own decisions, and for services to be co-designed. We now have to go a step further and truly produce services which are led by the needs of the individual, not the system.

CHAPTER ONE:

GETTING THE FOUNDATIONS RIGHT: COMMISSIONING FOR PREVENTION AND QUALITY CARE

Every person with a mental health problem should be able to say:
I am confident that the services I may use have been designed in partnership with people who have relevant lived experience.

People with lived experience of mental health problems, carers and health and social care professionals told the Taskforce that prevention was a top priority. Specific themes raised included support for new mothers and babies, mental health promotion within schools and workplaces, being able to self-manage mental health, ensuring good overall physical and mental health and wellbeing, and getting help early to stop mental health problems escalating. Many people discussed the importance of addressing the wider determinants of mental health, such as good quality housing, debt, poverty, employment, education, access to green space and tough life experiences such as abuse, bullying and bereavement. It was suggested that while it is particularly important to recognise loneliness in older people, these issues can affect people of any age.

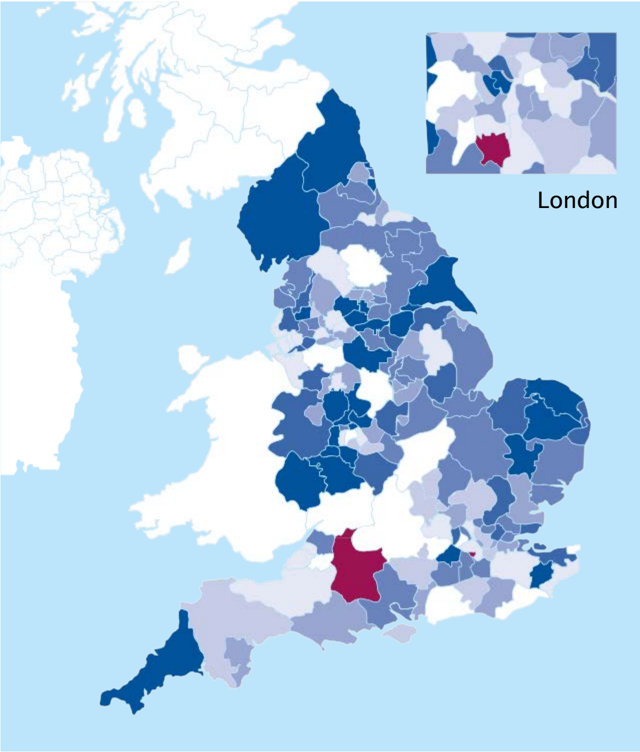
1.1 THE SYSTEM NOW

The quality of local mental health commissioning is variable. We found a twofold difference in apparent per-capita spend by CCGs, a more than threefold difference in excess premature mortality in people with mental health problems in England and a fourfold variation in mortality across local authorities. For children and young people there is wide variation in spend in both the NHS and local authorities. Detentions under the Mental Health Act continue to rise steadily year on year. Similarly, we know that many adults cannot get the right care locally, a clear demonstration of poor quality commissioning and a lack of investment to meet local need. Reductions in local authority budgets are also leading to rising pressures on important components of mental health care e.g. social care and residential housing.

Up to ~2x variation in per-capita spend, even when adjusted

Unadjusted spend shows 5x variation

Spend per PRAMH-weighted capita by CCGs and NHS England on mental health 2013/14
PRAMH model weights the population based on age, sex, prevalence of mental health conditions, markers of severity (e.g. MHA), accommodation and employment status, ethnicity and length of contact with mental health services



Lowest spend

Highest spend

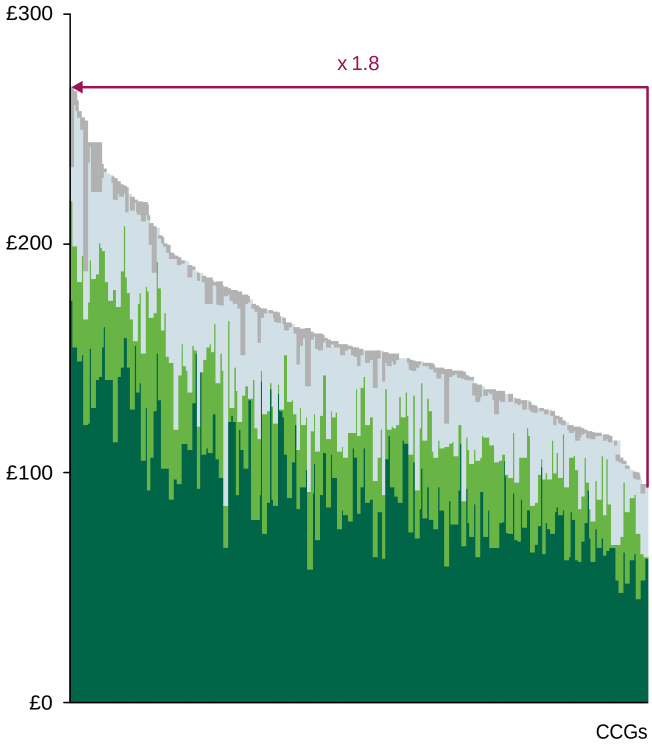
No Data

Other settings

All NHS England services

Inpatient (CCG)

Community and outpatient (CCG)



Note: Excludes 2 CCG; NHS England per capita expenditure varies by four regions (not by CCG). Source: Programme Budgeting 2013/14; Specialised Finance data; NHS England PRAMH weighted population

Commissioning of services is fragmented between CCGs, local authorities and the NHS. More needs to be done on prevention to reduce inequalities and there needs to be a greater focus on preventing suicide. There is increasing interest in “population-based” commissioning, either by pooling budgets or through joint decision-making with other commissioners, and a number of places are combining spending power across health and social care. The use of personal health budgets is increasing and other new models of care are being developed.

However, there is a long way to go to achieve integrated, population-based commissioning that is crucial for improving mental health outcomes, and incorporates specialised commissioning.

The Crisis Care Concordat action plans are promising as a model for integrated local commissioning. We also endorse the approach set out in Future in Mind as a model for wider system reform, which involves the NHS, public health, voluntary, local authority, education and youth justice services working together through Local Transformation Plans to build resilience, promote good mental health and make it easier for children and young people to access high quality care. This builds on a range of existing legislation that concerns children and young people and which requires agencies to take a coordinated approach. The plans are also important because they address the full spectrum of need, including children and young people who have a particular vulnerability to mental health problems.

Challenges remain to breaking down barriers between how services are commissioned across the country. Within the NHS, primary, secondary and tertiary care services should deliver integrated physical and mental health outcomes. Currently needs are addressed in isolation, if at all, which is not effective or efficient. CCGs need to ensure people with multiple needs do not fall through service gaps. For example, the commissioning of alcohol and substance misuse services has been transferred from the NHS to local authorities, leading to the closure of specialist NHS addiction inpatient units. Referral pathways have become more complex and many people with mental health and substance misuse problems no longer receive planned, holistic care.

On employment, the Department of Work and Pensions forecasts that it will spend £2.8 billion in total payments to contractors to help people into work under the Work Programme between June 2011 and March 2020. Yet fewer than one in 10 people with mental health problems have gained employment through the Work Programme. We know psychological therapies and Individual Placement and Support (IPS) services have proved highly effective – with around 30 per cent moving into jobs through IPS – but these are not being commissioned at scale. The Taskforce also welcomes the introduction of a Joint Unit for Work and Health, which is already piloting new approaches and recently secured significant new investment for an innovation fund.

Commissioners need support to analyse data, moderate demand, channel individuals to appropriate care and test their use of resources against their priorities. Co-production with clinicians and experts-by-experience to ensure services are accessible and appropriate for people of all backgrounds is also essential. Commissioners also need to understand what works, be adept at the use of financial and other levers, and be fully accountable for improving the mental health of their communities.

1.2 THE SYSTEM IN THE FUTURE

Local communities will be supported to develop effective Mental Health Prevention plans, and use the best data available to commission the right mix of services to meet local needs. Plans should focus on public mental health, including promoting good mental health, addressing the wider social determinants of mental health problems, local approaches to challenging stigma, and targeting at risk groups with proven interventions. This approach should blend healthcare, social care and user-led support.

By 2020/21, NHS commissioning will be underpinned by a robust understanding of the mental health needs of the local population, bringing together local partners across health, social care, housing, education, criminal justice and other agencies, with a clear recognition of the mental health needs of people treated for physical ailments and vice versa, and with greater integration across agencies to build stronger, more resilient communities. Commissioners will have the knowledge and skills to embed what is proven to work, and to work in partnership with people using services, carers, and local communities to develop and evaluate innovative new models in a range of settings.

The quality of services and outcomes will be assessed on the basis of robust data. There will be clear plans in place to prevent mental ill-health and suicide. More areas will have the freedom to work jointly across whole health and social care systems, following the examples of Manchester and West Midlands.

The Taskforce welcomes the invitation set out in NHS England Planning Guidance 2016/17 – 2020/21 for providers of secondary mental health services to manage budgets for tertiary (specialised) services, to reduce fragmented commissioning and improve care pathways. This is a significant change, which should be developed as a new vanguard programme, ensuring adequate inpatient resource is maintained while preparations are made to support people who are ready to transition into community based services. NHS England should also have established new models of care to trial this new approach for perinatal and CAMHS inpatient services.

Commissioners will:

- work in partnership with local stakeholders and voluntary organisations
- co-produce with clinicians, experts-by-experience and carers
- consider mental and physical health needs
- plan for effective transitions between services
- enable integration
- draw on the best evidence, quality standards and NICE guidelines
- make use of financial incentives to improve quality
- emphasise early intervention, choice and personalisation and recovery
- ensure services are provided with humanity, dignity and respect.

1.3 THE DELIVERY PLAN BY 2020/21

Health and Wellbeing Boards should have plans in place to promote good mental health, prevent problems arising and improve mental health services, based on detailed local data for risk factors, protective factors and levels of unmet need. These should specifically identify which groups are affected by inequalities related to poor mental health and be co-produced with local communities to generate innovative approaches to care and improving quality. Each local council should have Mental Health Champions, building on the 60 that already exist. Nationally, the Department of Health should lead continued work to tackle stigma.

Co-production with clinicians and experts-by-experience should also be at the heart of commissioning and service design, and involve working in partnership with voluntary and community sector organisations. Applying the 4PI framework of Principles, Purpose, Presence, Process and Impact developed by the National Survivor and User Network will help ensure services or interventions are accessible and appropriate for people of all backgrounds, ages and experience.

We expect rapid progress in the transformation of services for children and young people following investment of £1.4 billion over five years announced by the Government in 2014/15 (including additional money for eating disorders in children and young people). Plans are ready and these will be the first major programmes set out in this strategy to be delivered.

More people with common mental health problems should be supported into work through expanding integrated access to psychological therapies and employment support in primary care. Thousands more people accessing secondary mental health services should also be supported to find or keep a job through evidence based Individual Placement and Support services.

The NHS, local authorities, housing providers and other agencies should be working together locally to increase access to supported housing for vulnerable people with mental health problems. They should also be acting to share joint plans and information between local partners so that mainstream housing services play a more active role in preventing mental health problems arising.

While joint working between the CCG commissioners and other partners has been accepted for children and young people, further work is required across adult services. This offers a means of tackling the difficulties arising from the fracturing of commissioning pathways and escalating demand for inpatient services. Work is also required across secure services and the criminal justice system.

These are the opportunities – but there are also risks. There will be uncertainty about the role and function of commissioning as local geographies change, responsibilities shift, and budgets come under pressure. NHS England and the ALBs must be clear what they expect of commissioners and ensure they are supported.

The transformation we envisage will take a number of years and without clear information about what the best care pathways look like and good data on current levels of spending, access, quality and outcomes, it will be hard to assess the impact of organisational change and ensure mental health services are not disadvantaged. Priority should also be given to tackling inequalities and routine data must be made available so that there is transparency about how local areas are addressing age, gender, ethnicity, disability and sexuality in their plans.

We recognise that the new models of care will not be operating nationwide by 2020/21. Providers currently carry much of the risk and responsibility for improvements in quality and outcomes, with too little scrutiny of commissioning. In an increasingly devolved system, commissioners must remain responsible for meeting the needs of their local populations and must be properly held to account.

Recommendation 1: NHS England should continue to work with Health Education England (HEE), Public Health England (PHE), Government and other key partners to resource and implement Future in Mind, building on the 2015/16 Local Transformation Plans and going further to drive system-wide transformation of the local offer to children and young people so that we secure measurable improvements in their mental health within the next four years. This must include helping 70,000 more children and young people to access high quality mental health care when they need it. The CYP Local Transformation Plans should be refreshed and integrated into the forthcoming Sustainability and Transformation Plans (STPs), which cover all health and care in the local geography, and should include evidence about how local areas are ensuring a joined up approach that is consistent with the existing statutory framework for children and young people.

Recommendation 2: PHE should develop a national Prevention Concordat programme that will support all Health and Wellbeing Boards (along with CCGs) to put in place updated Joint Strategic Needs Assessment (JSNA) and joint prevention plans that include mental health and co-morbid alcohol and drug misuse, parenting programmes, and housing, by no later than 2017.

Recommendation 3: The Department of Health, PHE and NHS England should support all local areas to have multi-agency suicide prevention plans in place by 2017, reviewed annually thereafter and supported by new investment.

Recommendation 4: The Cabinet Office should ensure that the new Life Chances Fund of up to £30 million for outcome-based interventions to tackle alcoholism and drug addiction through proven approaches requires local areas to demonstrate how they will integrate assessment, care and support for people with co-morbid substance misuse and mental health problems. It should also be clear about the funding contribution required from local commissioners to pay for the outcomes that are being sought.

Recommendation 5: By 2020/21, NHS England and the Joint Unit for Work and Health should ensure that up to 29,000 more people per year living with mental health problems should be supported to find or stay in work through increasing access to psychological therapies for common mental health problems (see Chapter Two) and doubling the reach of Individual Placement and Support (IPS). The Department of Work and Pensions should also invest to ensure that qualified employment advisers are fully integrated into expanded psychological therapies services.

Recommendation 6: The Department of Health and the Department for Work and Pensions, working with NHS England and PHE, should identify how the £40 million innovation fund announced at the Spending Review and other investment streams should be used to support devolved areas to jointly commission more services that have been proven to improve mental health and employment outcomes, and test how the principles of these services could be applied to other population groups and new funding mechanisms (e.g. social finance).

Recommendation 7: The Department for Work and Pensions should ensure that when it tenders the Health and Work Programme it directs funds currently used to support people on Employment Support Allowance to commission evidence-based health-led interventions that are proven to deliver improved employment outcomes – as well as improved health outcomes – at a greater rate than under current Work Programme contracts.

Recommendation 8: NHS England should work with NHS Improvement to run pilots to develop evidence based approaches to co-production in commissioning by April 2018.

Recommendation 9: NHS England should ensure that by April 2017 population-based budgets are in place which give CCGs or other local partners the opportunity to collaboratively commission the majority of specialised services across the life course. In 2016/17, NHS England should also trial new models through a vanguard programme that allow secondary providers of these services to manage care budgets for tertiary (specialised) mental health services to improve outcomes and reduce out of area placements.

Recommendation 10: The Department of Health, Department of Communities and Local Government, NHS England, HM Treasury and other agencies should work with local authorities to build the evidence base for specialist housing support for vulnerable people with mental health problems and explore the case for using NHS land to make more supported housing available for this group.

Recommendation 11: The Department of Work and Pensions should, based on the outcome of the "Supported Housing" review in relation to the proposed Housing Benefit cap to Local Housing Allowance levels, use the evidence to ensure the right levels of protection are in place for people with mental health problems who require specialist supported housing.

Recommendation 12: The Department of Health should work with PHE to continue to support proven behaviour change interventions, such as Time to Change, and to establish Mental Health Champions in each community to contribute towards improving attitudes to mental health by at least a further 5 per cent by 2020/21.

CHAPTER TWO:

GOOD QUALITY CARE FOR ALL 7 DAYS A WEEK

Every person with a mental health problem should be able to say:
I have rapid access, within a guaranteed time, to effective, personalised care. I have a choice of talking therapy so that I can find one appropriate to me. When I need urgent help to avoid a crisis I, and people close to me, know who to contact at any time. People take me seriously and trust my judgement when I say a crisis is approaching. I can get help in a crisis, fast. Where I raise my physical health concerns, in any setting, they are taken seriously and acted on. If I am in hospital, staff on the wards can help with my mental as well as physical health needs. Services understand the importance to me of having friends, opportunities and close relationships.

The Taskforce heard that timely access to effective, good quality, evidence-based mental health pathways, with clear waiting times, is a primary concern. People also value having a choice of support, tailored to their specific needs, including access to a full range of psychological therapies. Access to treatment should be equal, and care should support people of all ages, regardless of the particular mental health problem they experience.

2.1 THE SYSTEM NOW

People who need physical health care – cancer care, for example – know what to expect and when to expect it. There are clear pathways of care, quality standards and maximum waiting times.

This is not always true of mental health care. Even though we know that the right care delivered in the right way at the right time improves and may save lives, mental health care has not benefited from the clear pathways and standards in place for secondary physical health care. Models of primary mental health care are also under-developed, and people with mental health problems are not always well supported in primary care with either their mental or physical health care needs.

The introduction of the first access and quality standards for mental health services therefore represents an important step forwards. Access to psychological therapies for common conditions such as anxiety and depression, as recommended by NICE, has increased. Work is in progress to improve services for people experiencing a first episode of psychosis, in perinatal care, crisis care and in children and young people's services, including for those with eating disorders.

What is lacking is a comprehensive set of standards – comparable to those for physical health care – and the supporting quality and outcomes data showing what works. Combined with under-investment, most people receive currently no effective care and too few benefit from the full range of NICE-recommended interventions.

Waiting times – for first appointments and for the right follow-on support – are unacceptably long. Basic interventions are in short supply, services are under pressure and thresholds for access are being raised. As a result, people's needs often escalate and they can become acutely unwell or experience a crisis, resulting in poorer outcomes and a reliance on higher cost care.

Crisis care is improving following the signing of the Crisis Care Concordat – but there is still a long way to go to match standards in urgent and emergency care for physical health needs. The Independent Commission on Acute Adult Psychiatric Care, established and supported by the Royal College of Psychiatrists, reported that the current reliance on acute beds means that it is often difficult for people to access care near home and that this is exacerbated by a lack of community services, particularly Crisis Response and Home Treatment Teams (CRHTTs). Only 14 per cent of adults experiencing a crisis feel they are provided with the right response and just over one third (36 per cent) feel respected by staff when they attend A&E. Less than half (48 per cent) of children and young people's services have a crisis intervention team. Too often people in crisis end up in a police cell rather than a suitable alternative place of safety.

Adult mental health services are under intense pressure. Less than half of CRHTTs have sufficient staff to provide 24/7 intensive home treatment as an alternative to admission, putting extra pressure on hospital beds. Delayed discharge and transfers of care are as high as 38 per cent in some areas, often linked to a lack of suitable housing or social care. Bed occupancy routinely exceeds 95 per cent and the CQC 'Right Here, Right Now' report found that many people have to travel long distances to be admitted.

Comprehensive liaison mental health services are currently available in only one in six (16 per cent) of England's 179 acute hospitals. The situation is better for paediatric mental health liaison, with 79 per cent of hospitals reporting cover, but these frequently do not operate out of hours.

Long stays in high cost secure hospitals and delayed discharge are common, often owing to the lack of recovery-focused care and suitable “step-down” services. Nine out of ten people in prison have a mental health or substance abuse problem – often together – but most do not receive the right care.

Some groups are disproportionately represented in detentions to acute and secure inpatient services, and are affected by long stays. For example, men of African Caribbean ethnic origin are twice as likely to be detained in low secure services than men of white British origin and stay for twice as long in those services on average. This suggests a failure to ensure equal access to earlier intervention and crisis care services.

Older people’s needs are also neglected, with many led to believe depression is a normal part of ageing.

People with mental health problems often also receive poorer physical health care. Those with severe mental illness die on average 15-20 years earlier than the general population. They are three times more likely to attend A&E with an urgent physical health need and almost five times more likely to be admitted as an emergency, suggesting deficiencies in the primary care they are receiving. The reverse is also true – people with long term physical health conditions do not routinely have mental health support included in their care package.

2.2 THE FUTURE: RIGHT CARE, RIGHT TIME, RIGHT QUALITY – 7 DAYS A WEEK

People with mental health problems, regardless of their age, ethnicity, or any other characteristic will have swift access to holistic, integrated and evidence-based care for the biological, psychological and social issues related to their needs, in the least restrictive setting and as close to home as possible.

By 2020/21, there will be a comprehensive set of care pathways in place and we expect at least a million more people will be able to get the help they need, improving outcomes and reducing reliance on acute care services. Services will provide clear data about access and waiting times and payment will be linked to the interventions delivered and the outcomes achieved.

There will be a 7 day NHS providing urgent and emergency mental health crisis care 24 hours a day, as there is for physical health, delivering 24/7 intensive home treatment and not just crisis assessment. Police cells will be used only in exceptional circumstances for people detained under the Mental Health Act. Good quality liaison mental health services will be available more widely across the country.

Mental and physical health support will be integrated. People with severe mental illness at highest risk of dying prematurely will be supported to access tests and screening to monitor their physical health in primary care. Mental health services will be delivered by multi-disciplinary integrated teams, with named, accountable clinicians, across primary, secondary and social care. They will include provision of care for substance misuse issues.

People with acute mental health needs will be able to access appropriate care, as inpatients or through community teams. Their housing, social care and other needs will be assessed on admission and the right support made available on discharge. Use of the Mental Health Act will be monitored, with a focus on Black and Minority Ethnic (BAME) groups.

People in the criminal justice system will also have their mental health needs assessed and the right care provided.

2.3 A DELIVERY PLAN FOR A 7 DAY MENTAL HEALTH SERVICE

Clinical standards, including maximum waiting times for NICE-recommended care based on the ambitions set out in Achieving Better Access to Mental Health Services by 2020/21 and the Five Year Forward View, should be rolled out nationwide. These must ensure that:

- waiting times are informed by clinical evidence and should be for effective care in line with NICE recommendations
- all services should routinely collect and publish outcomes data.

These are already in place for psychological therapies for common mental health problems, a waiting time standard for early intervention in psychosis will come into effect from April 2016 and one for children and young people with eating disorders the following year.

Urgent work is needed to establish comprehensive pathways and quality standards for the rest of the mental health system based on the timetable on page 36, which can then be implemented as funding becomes available. This programme must be co-produced with clinical experts and experts-by-experience. Work is already in happening to secure input on what robust standards for children and young people, crisis care for people of all ages, and perinatal care should look like. There should also be a referral to treatment access standard for acute care, including quality standards and outcomes measures for home treatment and inpatient care for people with acute mental health needs.

Where evidence about the effectiveness of interventions is robust and pathways are in place or are being developed there is a strong case for NHS England to invest to expand access. NHS England, the Department of Health and the Ministry of Justice should also start joint work to develop pathways across the criminal justice system.

Improved access to high quality inpatient services for children, young people and adults is needed, as highlighted by the Independent Commission on Acute Adult Psychiatric Care, established and supported by the Royal College of Psychiatrists which reported earlier this month.

Primary care (including Out of Hours services) should form a part of each of the relevant pathways within the new programme. There should also be a new focus in primary care on the physical health care of people with severe mental health problems, including psychosis, bipolar disorder and personality disorder.

Wherever it is provided care should be appropriate to people of all ages. Older people should be able to access services that meet their needs – bespoke older adult services should be the preferred model until general adult mental health services can be shown to provide age appropriate care.

Recommendation 13: By 2020/21, NHS England should complete work with ALB partners to develop and publish a clear and comprehensive set of care pathways, with accompanying quality standards and guidance, based on the timetable set out in this report. These standards should incorporate the relevant physical health care interventions and the principles of co-produced care planning.

Recommendation 14: NHS England should invest to increase access to integrated evidence-based psychological therapies for an additional 600,000 adults with anxiety and depression each year by 2020/21 (resulting in at least 350,000 completing treatment), with a focus on people living with long-term physical health conditions and supporting 20,000 people into employment. There must also be investment to increase access to psychological therapies for people with psychosis, bipolar disorder and personality disorder.

Recommendation 15: By 2020/21, NHS England should support at least 30,000 more women each year to access evidence-based specialist mental health care during the perinatal period. This should include access to psychological therapies and the right range of specialist community or inpatient care so that comprehensive, high quality services are in place across England.

Recommendation 16: The NHS should ensure that from April 2016 50 per cent of people experiencing a first episode of psychosis have access to a NICE–approved care package within two weeks of referral, rising to at least 60 per cent by 2020/21.

Recommendation 17: By 2020/21, NHS England should ensure that a 24/7 community-based mental health crisis response is available in all areas across England and that services are adequately resourced to offer intensive home treatment as an alternative to an acute inpatient admission. For adults, NHS England should invest to expand Crisis Resolution and Home Treatment Teams (CRHTTs); for children and young people, an equivalent model of care should be developed within this expansion programme.

Recommendation 18: By 2020/21, NHS England should invest to ensure that no acute hospital is without all-age mental health liaison services in emergency departments and inpatient wards, and at least 50 per cent of acute hospitals are meeting the 'core 24' service standard as a minimum.

Recommendation19: NHS England should undertake work to define a quantified national reduction in premature mortality among people with severe mental illness, and an operational plan to begin achieving it from 2017/18. NHS England should also lead work to ensure that by 2020/21, 280,000 more people living with severe mental illness have their physical health needs met by increasing early detection and expanding access to evidence-based physical care assessment and intervention.

Recommendation 20: PHE should prioritise ensuring that people with mental health problems who are at greater risk of poor physical health get access to prevention and screening programmes. This includes primary and secondary prevention through screening and NHS Health Checks, as well as interventions for physical activity, obesity, diabetes, heart disease, cancer and access to 'stop smoking' services. As part of this, NHS England and PHE should support all mental health inpatient units and facilities (for adults, children and young people) to be smoke-free by 2018.

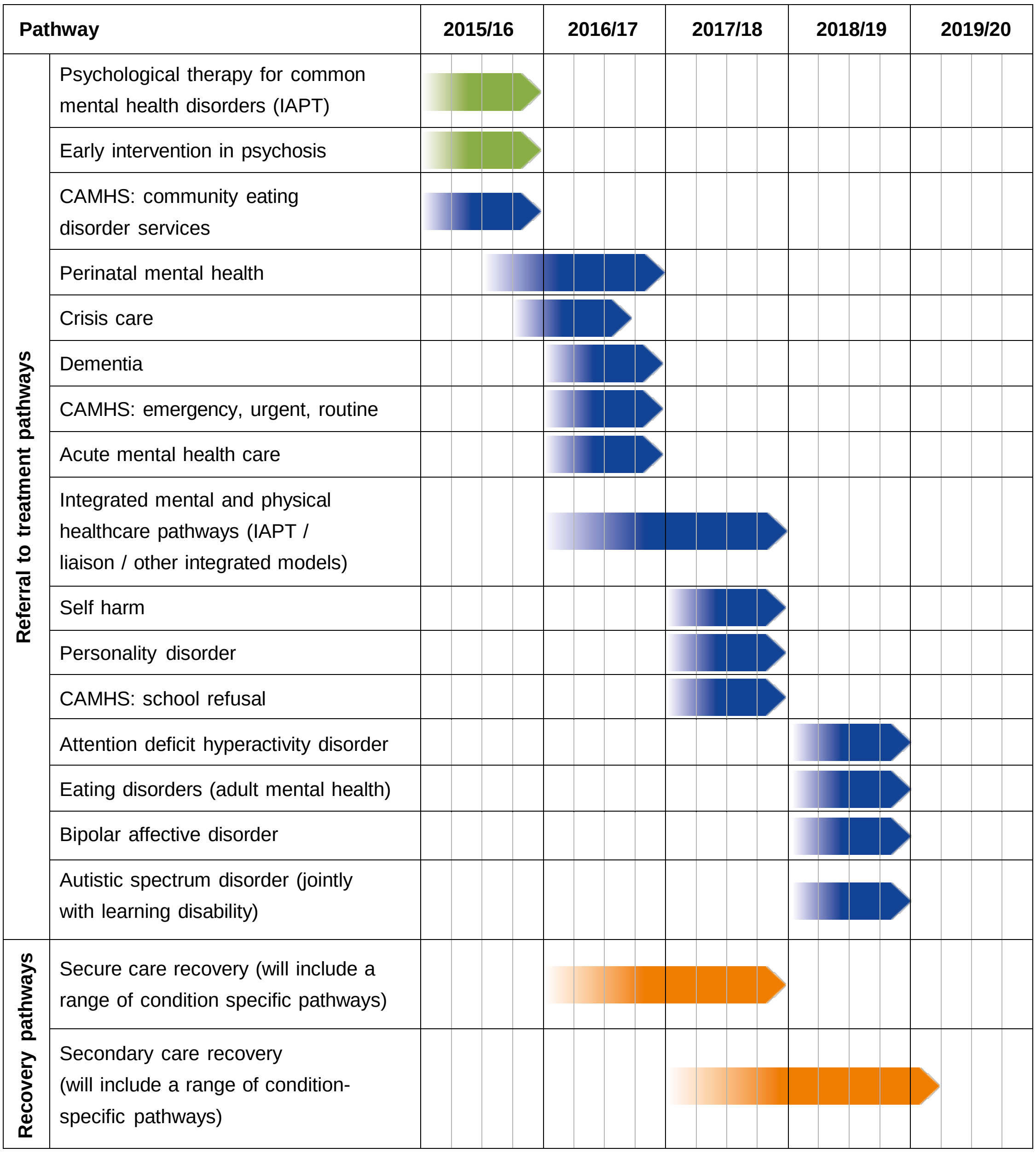
Recommendation 21: NHS England should ensure that people being supported in specialist older-age acute physical health services have access to liaison mental health teams – including expertise in the psychiatry of older adults – as part of their package of care, incentivised through the introduction of a new national Commissioning for Quality and Innovation (CQUIN) framework or alternative incentive payments, and embedded through the Vanguard programmes.

Recommendation 22: In 2016, NHS England and relevant partners should set out how they will ensure that standards are introduced for acute mental health care, with the expectation that care is provided in the least restrictive way and as close to home as possible. These plans should include specific actions to substantially reduce Mental Health Act detentions and ensure that the practice of sending people out of area for acute inpatient care as a result of local acute bed pressures is eliminated entirely by no later than 2020/21. Plans should also include specific action to substantially reduce Mental Health Act detentions and targeted work should be undertaken to reduce the current significant over-representation of BAME and any other disadvantaged groups within detention rates. Plans for introduction of standards should form part of a full response to the Independent Commission on Acute Adult Psychiatric Care, established and supported by the Royal College of Psychiatrists, by no later than end 2016/17.

Recommendation 23: NHS England should lead a comprehensive programme of work to increase access to high quality care that prevents avoidable admissions and supports recovery for people of all ages who have severe mental health problems and significant risk or safety issues in the least restrictive setting, as close to home as possible. This should seek to address existing fragmented pathways in secure care, increase provision of community based services such as residential rehabilitation, supported housing and forensic or assertive outreach teams and trial new co-commissioning, funding and service models.

Recommendation 24: The Ministry of Justice, Home Office, Department of Health, NHS England and PHE should work together to develop a complete health and justice pathway to deliver integrated health and justice interventions in the least restrictive setting, appropriate to the crime which has been committed.

Proposed mental health pathway and infrastructure development programme



	Pathway	2015/16	2016/17	2017/18	2018/19	2019/20
Referral to treatment pathways	Psychological therapy for common mental health disorders (IAPT)	🟩				
	Early intervention in psychosis	🟩				
	CAMHS: community eating disorder services	🟦				
	Perinatal mental health	🟦	🟦			
	Crisis care	🟦	🟦			
	Dementia		🟦			
	CAMHS: emergency, urgent, routine		🟦			
	Acute mental health care		🟦			
	Integrated mental and physical healthcare pathways (IAPT / liaison / other integrated models)		🟦	🟦		
	Self harm			🟦		
	Personality disorder			🟦		
	CAMHS: school refusal			🟦		
	Attention deficit hyperactivity disorder				🟦	
	Eating disorders (adult mental health)				🟦	
	Bipolar affective disorder				🟦	
	Autistic spectrum disorder (jointly with learning disability)				🟦	
Recovery pathways	Secure care recovery (will include a range of condition specific pathways)		🟧	🟧		
	Secondary care recovery (will include a range of condition-specific pathways)			🟧	🟧	

There are a number of different mental health conditions, and the guidelines and quality standards produced by NICE are structured in line with broad diagnostic categories such as ‘psychosis’. The aim of the existing mental health access and waiting time standards programme is to ensure that a greater number of people have timely access to the full range of interventions recommended by NICE and receive the ‘right care, first time’. The proposed new standards have broadly been framed in line with NICE guidelines and quality standards, unless this makes little practical sense. For example, the crisis care standards will cut across multiple conditions because the focus must be responding rapidly to people’s needs in the most appropriate setting (although the aim will still be to ensure that people in crisis have access to care in line with NICE recommendations). The proposed programme also includes work to ensure that people who are already receiving support get care that is fully NICE-concordant, including psychological therapy, as a core part of co-produced care plans that are recovery and outcome-focused.

CHAPTER THREE:

INNOVATION AND RESEARCH TO DRIVE CHANGE NOW AND IN THE FUTURE

3.1 BUILDING ON INNOVATION

Every person with a mental health problem should be able to say:
I am confident that the services I may use have been designed in partnership with people who have relevant lived experience. I can access support services without waiting for a medical referral. I am able to access a personal budget for my support needs on an equal basis to people with physical health problems for example, to help my recovery or to stay well. My mental and physical health needs are met together.

I am provided with peer support contact with people with their own experience of mental health problems and of using mental health services. I can find peer support from people who understand my culture and identity. Peer support is available at any point in my fluctuating health – in a crisis, during recovery, and when I am managing being well. I have a place I can call a home, not just 'accommodation'. I have support to help me access benefits, housing and other services I might need.

There were also concerns from people from BAME communities, who told us they had lost trust in services and wanted more support within the community. More widely, we heard that community and voluntary sector providers play a critical role in supporting groups that are currently poorly served by services, such as BAME communities, children and young people, older people, lesbian, gay, bisexual and transgender people, and people with multiple needs.

The Taskforce heard that there is a strong appetite for mental health research to be equitably funded and to have parity with other areas of health research. There was also support for much more research involving experts-by-experience, looking at what matters most to people in relation to prevention and care or support. Understanding the causes of mental ill health, including social and psychological factors, was considered a priority for research funding.

Delivering better care to more people not only requires increased investment. It also requires the development of new ways to improve the quality and productivity of services. We heard of many examples of approaches which had promise, but where further research was required.

This is already being applied: successful innovations, such as the Crisis Care Concordat, have led to the transformation of services, highlighting the importance of multi-agency partnerships and strong local leadership in implementing change. NHS Improvement should seek to stimulate other local initiatives building a broad pipeline of improvements from which others can learn.

Alongside new standards we need to see further innovation in three areas:

- **new models of care** to stimulate effective collaboration between commissioners and providers to develop integrated, accessible services for all - for example Integrated Personal Commissioning
- **expanding access to digital services** to enable more people to receive effective care and provide greater accessibility and choice - for example the digital initiative in London that will be operational later this year
- **a system-wide focus on quality improvement** to support staff and patients to improve care through effective use of data, with support from professional networks.

Innovation must be robustly evaluated as part of a strengthened approach to mental health research. NHS England should trial new approaches at scale, first in the 50 vanguard sites which are working to integrate health and social care, and second by creating an equivalent cohort of vanguard areas to pilot new approaches to delivering integrated specialist mental health care.

All new models must be developed in partnership with experts-by-experience, carers, and community and voluntary organisations. Psychological and social interventions, such as peer support and short-stay alternatives to hospital, are particularly valued by people with mental health problems and it is essential to demonstrate whether they also provide value for money.

We see a pivotal role for digital technology in driving major changes to mental health services over the next five years. There are already good examples of its use by NHS Choices, and there are a number of apps with a mental health theme. There is a large mental health community on social media and voluntary organisations report heavy demand on their digital services.

Provision must be increased so that:

- people can access services conveniently, have greater choice, and can network with peers to provide mutual support and guidance
- providers can deliver a more nuanced service, with contact through digital

media backed up by face-to-face interventions
- commissioners can improve outcomes through low-cost and easily scalable interventions
- providers can work securely to share patient data on electronic health records, where appropriate, to benchmark their performance and to test new service models
- people who use services, carers and the wider public can hold the system to account by using data across the entire pathway (from prevention and access through to productivity and outcomes) to scrutinise performance.

Our engagement activity brought home the critical role that people with experience of mental health problems, carers and staff can play in improving services. Yet we heard countless stories of promising ideas not being heard or taken forward. A whole-system approach is needed among the health ALBs to encourage constructive challenge.

Mental health problems account for a quarter of all ill health in the UK. Despite important new developments in mental health research it receives less than 5.5 per cent of all health research funding. Latest figures suggest that £115 million is spent on mental health research each year compared with £970 million on physical health research.

This disparity was highlighted by the Chief Medical Officer in her 2014 report. The biggest existing gaps include research into children's mental health, the promotion of good mental health and prevention of ill health, and the links between mental and physical health. One pound spent on mental health research realises an additional return of 37p each year, the same rate of return as for research on cancer and heart disease.

3.2 DELIVERING ON INNOVATION AND RESEARCH

We aim to create a simple pathway for innovation and research:

- identify areas of innovation and research promise
- invest in research programmes which include testing approaches at scale
- review research and embed it into care pathways and new models of care.

In future, new models of care will support people's mental health alongside their other needs, including physical health, employment, housing and social care and will have a greater emphasis on prevention, self-management, choice, peer support, and partnership with other sectors.

Specifically, new models of enhanced primary care and collaborative specialist care that meets the physical and mental health needs of people with severe mental illness will have been fully trialled.

People will also have greater choice and control over the services provided for them. They will be able to access good information, help and advice online, via live chat, email, text message and phone. Organisations will have the technology to collect data to improve their services. Mental health will be integrated into national and local transformation programmes and NHS commissioners supported to engage patients and staff in improving the quality and cost-effectiveness of care. There will be a more co-ordinated approach to research between government, private, public and philanthropic sectors over the long term and the involvement of people with lived experience of mental health problems as standard.

Mental health research should follow the roadmap set out in the ROAMER project, a collaboration of over 1,000 scientists, people using services, families, professional groups and industry representatives, published in September 2015, which identified the following priorities:

1. Preventing mental health problems arising, promoting mental health and focusing on young people
2. Focusing on the causal mechanisms of mental ill-health
3. Setting up international collaborations and networks for mental health research
4. Developing and implementing new and better interventions for mental health and wellbeing
5. Reducing stigma and empowering people with mental health problems and carers
6. Research into health and social systems.

3.3 NEW MODELS OF CARE

The new models of care being piloted by the vanguard sites offer opportunities to improve care for people with mental health problems by, for example:

- working with Primary and Acute Care Systems (PACS) to incorporate mental health screening and support within maternity pathways, and considering new payment models for integrating mental health care within tariff prices
- working with Multispeciality Community Providers (MCP) to provide integrated psychological support within wider primary care and community services provision, and supporting mental health inpatients more effectively to manage their physical health
- working with Urgent and Emergency Care (UEC) vanguards to ensure that sufficient liaison mental health and pathways to further care are available in acute hospitals to support those in mental health crisis.

NHS England should drive the development of new care models, starting with the implementation of NICE-recommended interventions. They should address current gaps in care and assess the work of relevant vanguards to benchmark how far mental health is reflected within their transformation plans to include:

- working with Jobcentre Plus, to expand access to IPS to help more people into employment
- trialling dedicated inpatient services for 16-25 year olds, as they transition to adulthood, following the model adopted for young cancer patients
- delivering extra training for primary care staff in supporting people with severe mental illness
- building a robust invest to save model for integrating psychological therapies into primary care through GP collaboratives
- developing new partnerships with the community and voluntary sector.

NHS England should support these innovations by working with current programmes to integrate commissioning across agencies, ensure commissioners and providers are confident to work in partnership with their communities, including people who use services and carers, and make more use of digital technology, as laid out in the National Information Board’s strategy. A co-ordinated approach across ALBs, backed by experts in clinical improvement and good quality data, is essential to give local leaders effective support to implement necessary change.

Recommendation 25: The MCP, PACS, UEC Vanguards and the Integrated Personalised Commissioning programme should be supported to ensure that the inclusion of payment for routine integrated care adequately reflects the mental health needs of people with long-term physical health conditions. Vanguard sites should also provide greater access to personal budgets for people of all ages, including children and young people who have multiple and complex needs, to provide more choice and control over how and when they access different services.

Recommendation 26: The UK should aspire to be a world leader in the development and application of new mental health research. The Department of Health, working with all relevant parts of government, the NHS ALBs, research charities, independent experts, industry and experts-by-experience, should publish a report one year from now setting out a 10-year strategy for mental health research. This should include a coordinated plan for strengthening and developing the research pipeline on identified priorities, and promoting implementation of research evidence.

Recommendation 27: The Higher Education Funding Council for England (HEFCE) should review funding requirements and criteria for decision-making to support parity through the Research Excellence Framework and take action to ensure that clinical academics in mental health (including in psychiatry and neuroscience) are not disadvantaged relative to other areas of health research, starting in 2016/17.

Recommendation 28: The Department of Health, through the National Information Board, should ensure there is sufficient investment in the necessary digital infrastructure to realise the priorities identified in this strategy. Each ALB should optimise the use of digital channels to communicate key messages and make services more readily available online, where appropriate, drawing on user insight. Building on trial findings, NHS England should expand work on NHS Choices to raise awareness and direct people to effective digital mental health products by integrating them into the website and promoting them through social marketing channels from 2016 onwards.

Recommendation 29: To drive and scale improvements in integration, the Department of Health and relevant partners should ensure that future updates to the Better Care Fund include mental health and social work services.

Recommendation 30: NHS England and NHS Improvement should encourage providers to ensure that ‘navigators’ are available to people who need specialist care from diagnosis onwards to guide them through options for their care and ensure they receive appropriate support. They should work with HEE to develop and evaluate this model.

Recommendation 31: NHS England should work with CCGs, local authorities and other partners to develop and trial a new model of acute inpatient care for young adults aged 16–25 in 2016, working with vanguard sites.

CHAPTER FOUR:

STRENGTHENING THE WORKFORCE

Every person with a mental health problem should be able to say:
Services and professionals listen to me and do not make assumptions about me. Those who work with me bring optimism to my care and treatment, so that I in turn can be optimistic that care will be effective. The staff I meet are trained to understand mental health conditions and able to help me as a whole person. Staff support me to be involved in decisions at the right level. They respond flexibly and change the way they work as my needs change. Wherever possible, there are people with their own experience of using services who are employed or otherwise used in the services that support me. As far as possible, I see the same staff members during a crisis.

My culture and identity are understood and respected when I am in contact with services and professionals. I am not stigmatised by services and professionals as a result of my health symptoms or my cultural or ethnic background. The strengths of my culture and identity are recognised as part of my recovery. My behaviour is seen in the light of communication and expression, not just as a clinical problem.

The Taskforce heard a strong message that staff across the NHS need to have training that equips them to understand mental health problems and to treat people with mental health problems with dignity and respect: treating ‘the person, not the diagnosis’. This is critical in enabling people with mental health problems to play a more active role in making choices about all aspects of their care, based on a more equal and collaborative relationship between the person and professional(s). A number of people described encountering stigmatising attitudes from some staff within mental health services, as well as staff in the wider NHS (including GP surgeries and non-clinical staff). Developing a paid peer support workforce had considerable support. People also wanted clearer protocols for staff when they are working with carers.

Professionals and professional bodies wanted the NHS as an employer to pay greater regard to the health and wellbeing of NHS and social care staff, as an effective way to improve the quality of care at a time when staff are under increasing pressure.

4.1 THE PICTURE TODAY - STAFF WORKING HARD IN A TOUGH ENVIRONMENT

Building and maintaining a qualified workforce of committed staff is one of the greatest challenges facing the NHS - and it is most acute in mental health. Providing specialist care to people experiencing mental distress is difficult, demanding work and requires exceptionally dedicated, caring individuals. It calls for multi-disciplinary teams, including psychiatrists, mental health nurses, psychologists, occupational therapists and social workers. There are significant opportunities for increasing access to high quality, integrated care that rely upon an expanded workforce with the right skills, but recruitment is not easy in some areas.

Data from 2014 from Health Education England (HEE) indicate a 6.3 per cent vacancy rate for NHS consultant psychiatrist posts, and over 18 per cent of core training posts in psychiatry are currently vacant. Psychiatry has the slowest rate of growth and the highest drop-out rate of any clinical specialty.

Between 2013/14 and 2014/15, referral rates increased five times faster than the Child and Adolescent Mental Health Services (CAMHS) workforce. Some areas report one in ten appointments cancelled because of staff shortages, specialist CAMHS run by junior staff who lack the requisite skills and too few therapists with the necessary training.

According to the King's Fund report 'Under Pressure' almost half of community mental health teams surveyed had staffing levels judged to be less than adequate in 2013/14 and many more were unable to provide a full multi-disciplinary team. Demand for temporary mental health nursing staff has risen by two thirds since the beginning of 2013/14. Staff shortages have contributed to deaths on inpatient wards, according to the 2015 National Confidential Inquiry into Suicide and Homicide by People with Mental Illness, and they have also been blamed for the rise in detentions.

Mind reported that in 2011/12, there were almost 1,000 incidents of physical injury following restraint in mental health services, with considerable variation between trusts. According to NHS Benchmarking, use of restraint has increased this year.

Workforce planning for mental health across the entire care pathway has not been developed and as a result opportunities are being missed to identify how changes in skill mix could help improve delivery, retain staff and tackle the highest vacancy rates.

A chink of light has appeared in the past year: there have been small increases in staffing on adult and older people's inpatient wards, driven by the safer staffing initiative and new initiatives to increase social workers in mental health. However, bed occupancy rates have also risen.

In 2015, a five year plan began, led by NHS England and HEE, to set staffing levels to deliver high quality care under the existing standards programme. For example, to meet the access standard for Early Intervention in Psychosis, this has identified what staffing needs are required including psychologists, therapists, care co-ordinators, vocational workers and psychiatrists. Further work is needed by NHS England and HEE to expand this programme to put into action the full range of pathways and standards described in Chapter Two.

Staffing is not just a question of numbers. The resilience and wellbeing of staff is also critical. Morale varies widely across the system today, linked with pressure of work and level of training, according to the Commission on Acute Adult Psychiatric Care, established and supported by the Royal College of Psychiatrists. Yet the Royal College of Physicians found fewer than half of NHS trusts had a plan in place to promote staff wellbeing.

It goes without saying that people seeking NHS care need to be treated with compassion. But what is sometimes forgotten is that staff do too. The care they receive impacts on the care they are able to deliver. Ten million working days are lost each year to sickness absence in the NHS. Some 43 per cent of mental health staff cite work related stress as the cause, second only to ambulance trusts at 51 per cent. Findings from the British Psychological Society and New Savoy staff wellbeing survey for 2015 show that around half of psychological professionals surveyed report depression. Seventy per cent say they are finding their job stressful. Yet the quality of the NHS occupational health service is inconsistent and, in some cases, inadequate, according to the NHS Health and Wellbeing Review.

Despite the pressures, we heard many positive and inspiring stories about the quality of care provided by NHS staff for people with mental health problems. We also heard that some have poor attitudes to mental health. The CQC report ‘Right here, Right now’ found less than four in ten people (out of 316 surveyed) accessing A&E felt listened to, taken seriously and treated with warmth and compassion. Among those in touch with specialist mental health crisis services the response was only slightly more positive with half (of 748 surveyed) saying they were well treated. GPs, ambulance staff and the police were perceived as more caring and voluntary organisations as being the most caring of all.

Race discrimination is still perceived by some as a problem according to the CQC. The introduction of the NHS Workforce Race Equality Standard is welcome and must be monitored closely.

Primary care staff are not yet fully equipped to provide high quality mental health care. More than four out of five practice nurses have responsibilities for which they have not been trained, with 42 per cent having no training at all in mental health, according to the Royal College of GPs. The training of GPs could also be improved to ensure they are fully supported to lead the delivery of multi-disciplinary mental health support in primary care.

Drugs for mental health problems can have serious side effects, such as causing rapid weight gain, but standards in the prescribing of anti-psychotics and other medications are not consistently adhered to, according to the Prescribing Observatory for Mental Health.

Shared decision-making between the person being supported and their practitioner is known to improve the quality of care by increasing active involvement, self-management and confidence. Yet less than half (42 per cent) of people using community mental health services "definitely" have a care plan and only just over half (56 per cent) said they were "definitely" involved as much as they wanted to be. New models are appearing. In secure care services, an approach to collaborative planning has been developed called My Shared Pathway which should be robustly evaluated.

Carers have a unique role to play for some people with mental health problems, and are often responsible for navigating complex health and social care systems and providing support to help the person manage. This includes the children of parents with mental health problems, who are likely to provide a caring role. Mental health practitioners should have the knowledge and skill to involve carers appropriately, including working with the person using the service and carers to determine what information can be shared between the three parties.

Peer support is highly valued, especially by young people and BAME adults, and should be developed as a core part of the multi-disciplinary team.

4.2 THE WORKFORCE IN THE FUTURE - MENTAL HEALTH AS THE PROFESSION OF CHOICE

As public interest and awareness of mental health increases and stigma diminishes, many more people are considering a career in mental health. The Think Ahead programme, a "Teach First" approach for social workers in mental health, has had in excess of 2,000 applicants for its first 100 places. There is the potential to put in place an approach that encourages more young people to choose a career in mental health, and more peer support.

The right workforce with the right skills is the single most important component of good care. All frontline staff, including those in the criminal justice system, should have basic skills to provide mental health care. Urgent work to jointly develop robust health and social care workforce planning for mental health must start now to:

- identify and fill workforce gaps
- provide the right training and support
- involve carers, as appropriate
- provide annual projections for staff numbers and costs.

The ‘Public mental health leadership and workforce development framework’ has been published by Public Health England. It should be implemented in full. Staff should be trained to prevent ill health, working across traditional boundaries, in line with its recommendations. The need for access to effective social work as part of good quality mental health care should also be recognised through the routine inclusion of social workers in NHS commissioner and provider workforce planning.

Mental health staff should be trained to treat people with sensitivity, in the least restrictive way possible, prescribing in line with standards and using restraint only in exceptional circumstances. There should be a greater focus on mental health awareness for all front-line staff. This will involve cultural change and require strong leadership.

Staff should work in partnership with the people using services to develop plans based on the personal goals of the individual. Peer support should be offered from people who have had similar experiences and carers should be given help to play an appropriate role. Restraint will be used only as a last resort.

By 2020/21, measures to improve staff morale and wellbeing will be in place, backed by good data, and people with mental health problems will experience an improvement in staff attitudes. Training will have been strengthened and new models of care expanded. Most care should be provided in community and primary care settings.

Protecting the mental health of the workforce is also vital. NHS England has committed to helping staff make choices to improve their own health, and mental health is a key part of that. This should apply across the NHS – building on positive initiatives within ambulance trusts. Every NHS trust should become an ‘enabling’ environment, as recommended in the Francis Report, so people want to work there. Trusts should monitor the mental health of their staff and provide effective occupational health services.

Recommendation 32: HEE should work with NHS England, PHE, the Local Government Association and local authorities, professional bodies, charities, experts-by-experience and others to develop a costed, multi-disciplinary workforce strategy for the future shape and skill mix of the workforce required to deliver both this strategy and the workforce recommendations set out in Future in Mind. This must report by no later than 2016.

Recommendation 33: NHS England should ensure current health and wellbeing support to NHS organisations extends to include good practice in the management of mental health in the workplace, and provision of occupational mental health expertise and effective workplace interventions from 2016 onwards.

Recommendation 34: NHS England should introduce a CQUIN or alternative incentive payment relating to NHS staff health and wellbeing under the NHS Standard Contract by 2017.

Recommendation 35: NHS England should develop and introduce measures of staff awareness and confidence in dealing with mental health into annual NHS staff surveys across all settings.

Recommendation 36: The Department of Health and NHS England should work with the Royal College of GPs and HEE to ensure that by 2020 all GPs, including the 5,000 joining the workforce by 2020/21, receive core mental health training, and to develop a new role of GPs with an extended Scope of Practice (GPwER) in Mental Health, with at least 700 in practice within 5 years.

Recommendation 37: The Department of Health should continue to support the expansion of programmes that train people to qualify as social workers and contribute to ensuring the workforce is ready to provide high quality social work services in mental health. This should include expanding 'Think Ahead' to provide at least an additional 300 places.

Recommendation 38: By April 2017, HEE should work with the Academy of Medical Royal Colleges to develop standards for all prescribing health professionals that include discussion of the risks and benefits of medication, and take into account people's personal preferences, including preventative physical health support and the provision of accessible information to support informed decision-making.

CHAPTER FIVE:

A TRANSPARENCY AND DATA REVOLUTION

The Taskforce heard from a range of stakeholder organisations that data and transparency are critical aspects of a system that delivers good outcomes. Work needs to happen to link data from different public services and agencies (the NHS, social care, education, criminal justice and others) to help identify and meet the full needs of people with mental health problems. Similarly, there should be more national support with the analysis and presentation of raw data to support good commissioning and local planning.

Organisations representing different communities emphasised the importance of equalities monitoring by providers for greater transparency about access, quality and outcomes for various groups. This should help ensure that the provisions of the Human Rights Act and the Equalities Act 2010 are being met. Several organisations also stated that there needs to be greater transparency in how resources are allocated to mental health across NHS settings, the quality of services provided and to what extent they are improving outcomes.

5.1 A “BLACK HOLE” OF DATA

Understanding how quickly people are able to access services, what sort of care they are receiving and what outcomes they are experiencing is vital to good care. Consistent and reliable data in mental health, however still lags behind other areas of health. There is good information available, but it is not co-ordinated or analysed usefully.

National data are collected through the Mental Health Services Data Set (MHSDS) by the Health and Social Care Information Centre (HSCIC) on behalf of the Department of Health. The MHSDS began operating on 1 February 2016 and its reporting capability is yet to be tested.

Prior to that point data reporting has been sporadic and the HSCIC has warned it will not be able to meet reporting needs quickly now the MHSDS is operational. Changes to the dataset can take more than 12 months which will limit the immediate usefulness of the MHSDS. For adults, data is also grouped together under ‘clusters’ which can inform how services are paid for but do not align with diagnosis or NICE guidelines so it not clear whether people are getting recommended interventions. The ‘cluster’ currency provides an indication of individual need and has demonstrated the ability of services to report high quality data (the cluster currency has been mandatory for providers since 2012). However, this approach still does not provide the right kinds of incentives i.e. across pathways of care or to promote good outcomes. It may even encourage perverse incentives, such as paying more where people move into crisis or become acutely unwell.

Some datasets are better quality than others – for example the national data on access to psychological therapies for common mental health problems are robust. Collection of data on children and young people has been subject to delays and the data itself lacks clarity. We also do not have ready access to local and national equalities data, showing us breakdowns in access and outcomes across groups protected by the Equality Act 2010.

The National Mental Health Intelligence Network (NMHIN), run by PHE, with support from NHS England and the Department of Health, presents data to help improve commissioning and service provision. In some areas, it is well developed, providing details on levels of access, spending and social care. But it lacks the analytical capacity of other health data networks. PHE publishes additional resources for children and young people on the Chimat website although it also lacks analytic power.

Financial reporting is an important indicator for scrutinising commissioning and provision. Yet it is not consistently available in mental health. Provider level data is also linked to care ‘clusters’ and reference costs for the clusters vary hugely across the country, partly due to lack of consistency in their use and partly to variations in the services provided. Clusters describe the needs that people present with but do not clearly align with the care that NICE recommends, making it difficult to establish the true funding picture. While CCG programme budgets for physical health are broken down by disease, there is only one category for mental health. Local information on investment in care, by condition, is therefore essential.

An important barrier to good care is the lack of appropriate data sharing to enable organisations to identify co-morbidities, anticipate problems and plan care in a holistic fashion. People with poor mental health may require primary care, secondary physical care and social care, as well as mental health services, but the lack of linked datasets hinders effective provision.

The Summary Care Record (SCR) is an attempt to address this by including key primary care information about an individual such as medication, allergies and adverse reactions. But it does not routinely include care plan information or allow access to mental health care records (or physical care records) which is a significant missed opportunity.

Good data are also necessary to allow people to make an informed choice of service. However, the information on mental health on ‘myNHS’ is limited to CQC ratings and clinical audits. Waiting times for care and the range of interventions on offer would be more relevant to choosing a provider.

5.2 A TRANSPARENCY REVOLUTION

The inadequacy of good national mental health data and the failure to address this issue until recently has meant that decisions are taken and resources allocated without good information, perpetuating a lack of parity between physical and mental health care.

This lack of transparency has also had a negative impact on confidence in mental health services - we heard that many people felt that additional resources didn’t reach the front line. Data about outcomes and acceptable levels of variation are unclear, but we are encouraged by the work of the NHS Benchmarking Network.

In the future, the quality of mental health services and how well they are meeting the needs of the local population will be demonstrated through the provision of accurate, relevant, timely data which will be collected routinely for each person with mental health problems receiving care.

National datasets will include information on diagnosis, interventions and outcomes and be appropriately linked with other datasets, such as for physical health and social care. The Department of Health, NHS England and PHE will lead the transformation in mental health information, with changes to HSCIC data collection backed by new funding.

The NMHIN and Chimat will provide comprehensive data resources to inform good quality commissioning and allow services to be benchmarked against each other, highlighting best practice and ensuring resources can be targeted where they have most impact. Commissioners will be able to assess prevalence, predict incidence and plan provision and identify individuals repeatedly admitted to inpatient care in order to target them for preventive interventions.

Budget reporting will be aligned to specific mental health conditions, increasing transparency. Everyone will be able to assess the responsiveness of services to local population needs, including the needs of marginalised groups covered by equalities legislation.

People using mental health services will be able to make informed choices about their care and how their data is used. Care will be increasingly personalised and measures will capture how well it is helping them achieve their goals. Individuals will be able to rate services, holding commissioners and providers to account.

5.3 PUTTING IN PLACE DATA PLANS

Providing high quality mental health care requires the collection of the right kind of mental health data, at the right time. The National Information Board has been charged with delivering this ambition. Their task now should be a national stock take of mental health data to ensure it includes the most meaningful measures, which align with national priorities, and that collecting it does not place undue pressures on clinicians and service managers. Clinical system suppliers, mental health commissioners, providers and experts-by-experience should be involved.

The transition to the MHSDS provides an opportunity to reconsider which data should be collected and reported. The HSCIC should develop a package of support to solve problems related to getting, using or sharing data.

More work is needed to ensure data can be linked across public agencies, to promote integration of care and generate insight into where people are accessing different parts of the system and, ultimately, what their needs, preferences and outcomes are.

PHE should work with other national agencies to develop the NMHIN as the trusted national repository of robust and publicly available mental health data and intelligence over the next 5 years.

A review of national clinical audits and how they supplement mandated datasets should be carried out, including the Prescribing Observatory for Mental Health UK, the National Audit of Schizophrenia and NHS Benchmarking club data. ‘Future in Mind’ also identified significant gaps in data on children and young people’s mental health and these must be addressed.

Recommendation 39: The Department of Health, NHS England, PHE and the HSCIC should develop a 5-year plan to address the need for substantially improved data on prevalence and incidence, access, quality, outcomes, prevention and spend across mental health services. They should also publish a summary progress report by the end of 2016 setting out how the specific actions on data, information sharing and digital capability identified in this report and the National Information Board's Strategy are being implemented.

Recommendation 40: The Department of Health should develop national metrics to support improvements in children and young people's mental health outcomes, drawing on data sources from across the whole system, including NHS, public health, local authority children's services and education, to report with proposals by 2017.

Recommendation 41: The Department of Health, HSCIC and MyNHS, working with NHS England, should improve transparency in data to promote choice, efficiency, access and quality in mental health care, ensuring that all NHS-commissioned mental health data are transparent (including where data quality is poor) to drive improvements in services. The CCG Performance and Assessment Framework should include a robust basket of indicators to provide a clear picture of the quality of commissioning for mental health. To complement this, NHS England should lead work on producing a Mental Health Five Year Forward View Dashboard by the summer of 2016 that identifies metrics for monitoring key performance and outcomes data that will allow us to hold national and local bodies to account for implementing this strategy. The Dashboard should include employment and settled housing outcomes for people with mental health problems.

Recommendation 42: NHS England and the HSCIC should work to identify unnecessary data collection requirements, and then engage with NHS Improvement to prioritise persistent non-compliance in data collection and submission to the MHSDS, and take regulatory action where necessary.

Recommendation 43: During 2016 NHS England and PHE should set a clear plan to develop and support the Mental Health Intelligence Network over the next five years, so that it supports data linkage across public agencies, effective commissioning and the implementation of new clinical pathways and standards as they come online.

Recommendation 44: By 2020/21, NHS England and NHS Improvement should work with the HSCIC and with Government to ensure rapid using and sharing of data with other agencies. The Department of Health should hold the HSCIC to account for its performance, and consult to set minimum service expectations for turning around new datasets or changes to existing datasets by no later than summer 2016.

Recommendation 45: The Department of Health and HSCIC should advocate the adoption of data-rich Summary Care Records that include vital mental health information, where individuals consent for information to be shared, by 2016/17.

Recommendation 46: The Department of Health should commission regular prevalence surveys for children, young people and adults of all ages that are updated not less than every seven years.

CHAPTER SIX:

INCENTIVES, LEVERS AND PAYMENT

The Taskforce heard from a number of stakeholder organisations that the way services are contracted and paid for affects the quality of care people receive across settings. This includes a lack of transparency and accountability associated with the use of ‘block contracts’ which do not specify how many people will be supported by the service or the quality of care they should receive. The Taskforce also heard that the way services are currently paid for can prevent them from being integrated e.g. acute physical health services are not paid to include mental health support, even though this is good practice. Organisations said that the development of more effective payment models is heavily dependent on robust data about the quality of services.

6.1 THE CURRENT APPROACH TO AN UNEVEN PLAYING FIELD

Mental health services have been plagued by years of under investment. More than half of mental health trusts are paid using block contracts providing a fixed amount unrelated to how local needs are being met or the quality of care provided. This rewards those that deliver low cost interventions, regardless of outcome, and penalises those that increase access or deliver more costly interventions, even though they may improve outcomes. This payment method also affects the development of personalisation in mental health care, since without more detailed information about individuals receiving care, the costs of that care, or clear care pathways, it is difficult for funding to be released through Personal Health Budgets or integrated with social care funding to support Integrated Personal Commissioning (combined personal budgets).

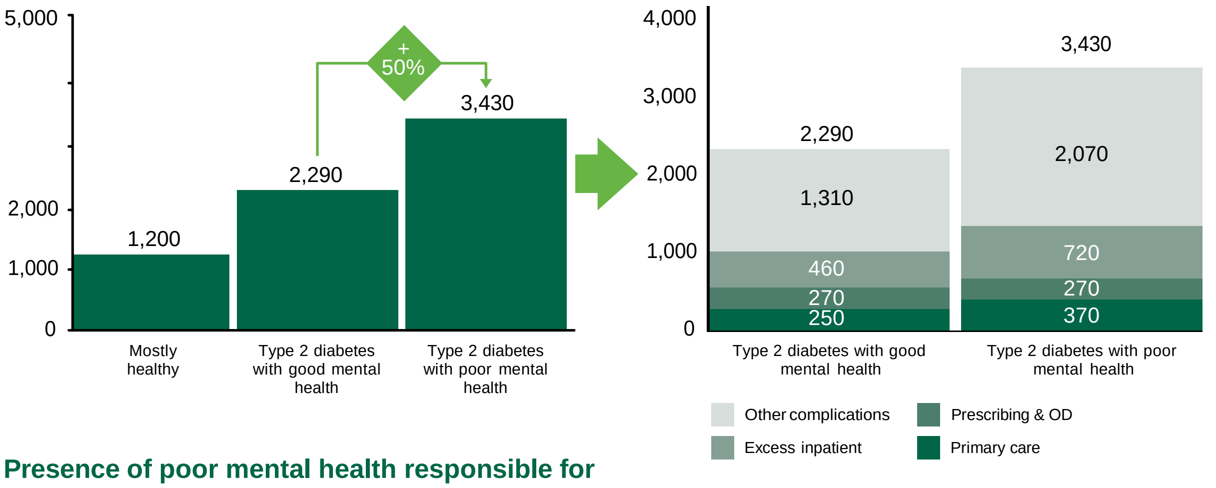
Some areas are moving away from block contracts but mental health is being left behind and thus lacks the financial levers to drive change. National guidelines to reward quality and outcomes are being poorly implemented at local level. There is also a risk that new models of care will make greater use of block contracts, which is not currently appropriate for payment of mental health interventions where there is little transparency around quality and outcomes.

However, new payment approaches are being developed. Care clusters, mandated since 2012, which aim to describe a group of people with similar mental health needs, are being used by a number of providers as the basis for payment. They have been criticised for not easily mapping to diagnoses, missing the complexity of some populations and failing to incentivise outcomes but they have provided an indication of need. Very few providers have moved to contracts that reward quality and outcomes.

Two new payment models are proposed for adult care in 2016/17 (for 2017/18). One is based on the year of care or episode of care appropriate to each of the mental health care clusters. The second is a capitation-based payment tied to care clusters or similar data. Both link payment in part to quality and outcome measures. NHS Improvement and NHS England are asking commissioners and providers to adopt one of the two approaches.

Several of the vanguard sites are adopting the capitation model but are using historic spending to set annual budgets. This risks reinforcing previous underinvestment. Some CCGs are developing local outcomes-based contracts. This is also encouraging but without a national approach, opportunities to share evidence about which models deliver the best outcomes may be lost.

Presence of poor mental health drives a further 50% increase in costs



Physical healthcare costs 50% higher for type 2 diabetics with poor mental health

Annual physical healthcare costs per patient, 2014/15 (£)

Additional costs due to increased hospital admissions and complications

Annual physical healthcare costs per patient, 2014/15 (£)

Presence of poor mental health responsible for £1.8bn of spend on type 2 diabetes pathway

Note: Does not include spend on prescribing psychiatric drugs and other mental health services
Source: Hex et all, 2012; APHO Diabetes Prevalence Model for England 2012; Long-term conditions and mental health: The cost of co-morbidities, The King's Fund

Better integration with physical health is vital but payment models do not incentivise this. For example, payments for diabetes and cancer care do not routinely cover psychological interventions and payments for mental health care do not ensure physical health needs are met as standard.

There is one national CQUIN that rewards mental health providers for ensuring that the physical health needs of people with psychosis are met. This supports working relationships between specialist mental health providers and primary care which can avoid relapses and crises. Introduction of the CQUIN has seen physical care monitoring rise by a third, but performance is still well below target.

6.2 A FUTURE APPROACH TO A LEVEL PLAYING FIELD

In future, payments should incentivise swift access, high quality care and good outcomes, while deterring cherry picking of people who seem ‘easiest-to-treat’. Payment models should include a range of capitated or population-based approaches. Wider levers include the NHS standard contract, CQUINs, quality premiums, sanctions and regulation, which should be used to encourage good performance. A full set of principles underpinning what the new approach to payment in mental health should look like is annexed.

Payments should incentivise provision of integrated mental and physical healthcare and be adjusted to account for inequalities. Funding decisions should be transparent and public, including those of the independent Advisory Committee for Resource Allocation (ACRA) for the NHS.

NHS England and NHS Improvement will need to provide robust support to providers and commissioners to introduce new payment approaches for adult mental health based on either capitated or episodic/year-of-care payment models and which reward improved outcomes, quality and access. Where progress is not being made, regulation, assurance and enforcement may be necessary. Similar changes are needed for children and young peoples’ services and psychological therapy services, and to incentivise the provision of mental health care to people with physical health problems.

Physical health providers will need to be reimbursed for meeting mental health needs which may require re-classification of patient care described by Healthcare Resource Groups (HRGs), Treatment Function Codes (TFCs) and Office of Population Censuses and Surveys Classification of Surgical Operations and Procedures (OPCS) codes.

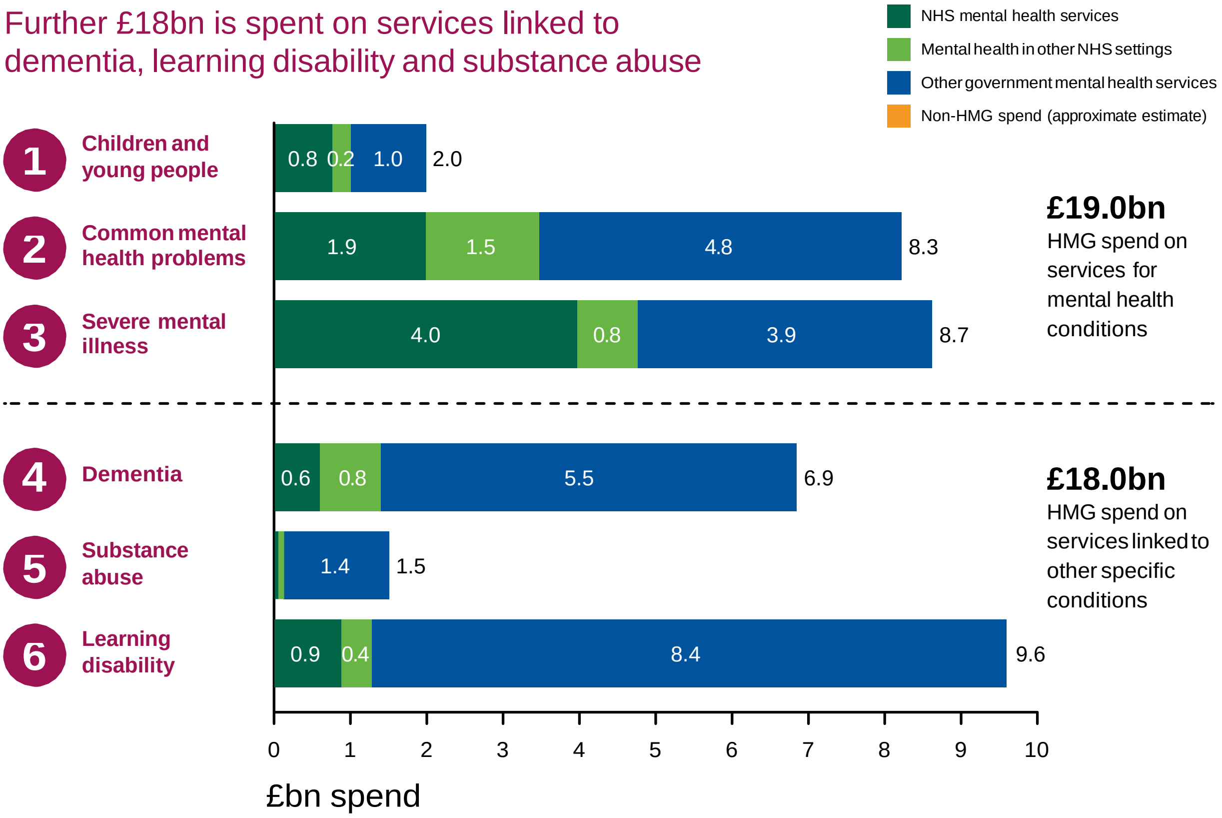
A new CQUIN to improve the recognition and treatment of depression in older people should be introduced, modelled on the dementia CQUIN. Since its introduction, the dementia CQUIN has raised the profile of the disease in general acute hospitals, and is now finding 90 per cent of people with possible dementia.

NHS funding formulae must be reviewed by ACRA to ensure they support parity between mental and physical health. They should also be reviewed to ensure it correctly estimate the prevalence and incidence of conditions across the mental health spectrum.

In respect of the annual inequalities adjustment given to CCGs for people with the poorest access and outcomes in health, CCGs should also report how their spending is related to need, access and outcomes for mental health. Mental health funding should be allocated to individual conditions in the same way as physical health funding to make it easier to track. Good quality data will be needed to determine whether care is cost-effective and whether new approaches are more appropriate than existing ones.

£19bn is spent on services for mental health conditions

Further £18bn is spent on services linked to dementia, learning disability and substance abuse



Note: Dementia healthcare expenditure only includes spend on mental health services for dementia, not on physical health co-morbidities (e.g. diabetes), which would increase spend by £3bn

Recommendation 47: NHS England and NHS Improvement should together lead on costing, developing and introducing a revised payment system by 2017/18 to drive the whole system to improve outcomes that are of value to people with mental health problems and encourage local health economies to take action in line with the aims of this strategy. This approach should be put in place for children and young people's services as soon as possible.

Recommendation 48: NHS England should disaggregate the inequalities adjustment from the baseline funding allocation for CCGs and primary care, making the value of this adjustment more visible and requiring areas to publicly report on how they are addressing unmet mental health need and inequalities in access and outcomes.

Recommendation 49: ACRA should review NHS funding allocation formulas, including the inequalities adjustment, to ensure it supports parity between physical and mental health in 2016/17. They should also be reviewed to ensure they correctly estimate the prevalence and incidence of conditions across the mental health spectrum. Membership of ACRA should be revisited with the specific goal of ensuring that mental health expertise is adequately represented across the disciplines involved, e.g. clinical, academic, policy and providers.

Recommendation 50: The Department of Health and NHS England should require CCGs to publish data on levels of mental health spend in their Annual Report and Accounts, by condition and per capita, including for children and Adolescent Mental Health Services, from 2017/8 onwards. They should require CCGs to report on investment in mental health to demonstrate the commitment that commissioners must continue to increase investment in mental health services each year at a level which at least matches their overall allocation increase.

CHAPTER SEVEN:

FAIR REGULATION AND INSPECTION

Every person with a mental health problem should be able to say:
I feel safe. My strengths, skills and talents are recognised and valued. I am treated as a person, not just according to my behaviour. My personal goals are recognised by support services. I choose who to consider the people ‘close to me’, who can support me in achieving mental wellbeing. I am able to see or talk to friends, family, carers or other people who I say are ‘close to me’ at any time. I can determine different levels of information sharing about me. I am confident that if I need care or treatment, timely arrangements are made to look after any people or animals that depend on me. I feel confident that my human rights are respected, protected and progressively realised in all systems of regulation and inspection.

If I raise complaints or concerns about a service these are taken seriously and acted upon, and I am told what has happened in response. If I do not have capacity to make decisions about my care and treatment, any advance statements or decisions I have made will be respected. I am supported to develop a plan for how I wish to be treated if I experience a crisis in future. As far as possible, people who see me in a crisis follow my wishes and any plan I have previously agreed. When I need medicines, their potential effects – including how they may react with each other – are assessed and explained.

7.1 THE SYSTEM TODAY: HIGH LEVELS OF SCRUTINY PAINTING A MIXED PICTURE OF EXPERIENCE

Many stakeholders believe that the legislative and regulation framework underpinning mental health care can be improved.

The Mental Health Act 1983 provides a legal framework for the detention of individuals with mental health problems in order to be assessed and treated (including with medication) for mental illness without regard to their mental capacity or their ability to give or withhold consent. This applies if they have a mental illness which requires assessment or care in a hospital and they are detained because they are assessed as posing a risk to themselves or others.

The Mental Capacity Act 2005 makes no distinction between the mental and physical with regard to decisions about care. But the 2005 Act's provisions about having the mental capacity to consent to care can be over-ridden in the case of mental health care by the 1983 Act. We heard that this can act as a barrier to making parity of esteem a reality because it enshrines differences in the treatment of people with mental and physical health problems and frames care as a method of social control rather than a therapeutic intervention. The 1983 Act should therefore be reviewed as part of the continuing drive for greater parity with physical healthcare.

Commissioners, providers and the CQC should ensure that the full range of people's human rights are protected at a time when their capacity, autonomy, choice and control may be compromised. This is reinforced by the Care Act 2014. However, the number of people detained and the number subject to restrictive Community Treatment Orders (CTOs) requiring them to adhere to particular interventions, including medication, continue to increase. The use of CTOs is much higher than anticipated when they were introduced in 2008, yet findings from a recent Oxford University study show they are not effective for the majority of people.

The Health and Social Care Act 2012, as reflected in the NHS Constitution, provides rights to specialist care, including access to consultant-led treatment within 18 weeks of referral and a choice of provider. However, there is not yet parity between an individual's rights to physical and mental health care. Although the right to choice of provider has been extended to mental health there is no legal right to recommended interventions or maximum waiting times, as there is for physical health care.

The CQC has a robust approach to regulating the quality of NHS service provision. However, inspection of mental health support in primary and acute physical health care settings should be strengthened. We must also ensure psychological therapies are properly regulated.

The only detailed measure of people's experience of mental health care is through the CQC survey of community mental health services. But this is inadequate, as revealed by the CQC's special inquiry into crisis care which showed that people's experiences of mental health care across other settings were very mixed and should be tracked on a regular basis. There is also no measurement of people's experience of inpatient mental health care, including secure care, despite the nature of compulsory treatment and the potential vulnerability of those who are detained, in some cases for months or years.

The Taskforce heard that the experience for people who are marginalised needs to be improved, with particularly strong messages coming through from BAME groups. The Workforce Race Equality Standard is a welcome development in the NHS for those providing services. But there is no equivalent for those accessing them. The 5-year Delivering Race Equality programme concluded in 2010 that there had been no improvement in the experience of people from minority ethnic communities receiving mental health care. Data since shows little change. These inequalities must be prioritised for action, and we support the recommendations of The Independent Commission on Acute Adult Psychiatric Care, established and supported by the Royal College of Psychiatrists on this issue.

There were 198 deaths of people detained under the Mental Health Act in 2013/14, the majority of which were due to natural causes, including preventable physical ill health. Care providers must ensure that they take appropriate steps to prevent the avoidable deaths of people in inpatient care, including people of all ages who are deprived of liberty through detention under the Mental Health Act. However, unlike in prison or police detention, where every death is independently investigated, there is no independent pre-inquest process in place for investigating these deaths. Care organisations themselves carry out internal investigations. As highlighted by the recent findings within Southern Health NHS Foundation Trust, the quality of internal investigations can be poor and providers are not always able to demonstrate robustly how they have learned from them and made improvements.

There are no published death rates in individual units or by CCG area, no information on whether death has occurred in a public or privately run organisation, and no information on the number or nature of deaths that have occurred in specific settings. Patterns of deaths that merit closer examination may thus escape public scrutiny. In particular, there are questions about the over-representation of black people in mental health settings and the use of force that features in some of their deaths. There is also very limited information available nationally on the number of children who have died in mental health settings.

Measurement of wider social outcomes – such as finding a job and accommodation – is also a marker of the quality of services and varies across organisations. Yet these outcomes can be more meaningful than strictly clinical outcomes such as being “symptom free”.

THE SYSTEM IN THE FUTURE

The full range of regulatory levers will be used to address inequalities and improve the quality and experience of people receiving mental health care. The right to equal treatment in the least restrictive setting will be clearly enshrined in legislation, and all providers will ensure they work in accordance with Human Rights legislation.

Strengthened inspection of mental health care by the CQC will be extended to all NHS-funded providers, including primary and acute physical health care. Measures of quality will show how services compare and specialist mental health services, including inpatient care, will include self-reported outcomes. Racial and other inequalities in rates of detention will be addressed and there will be greater transparency in the causes of deaths and how they can be prevented.

SYSTEM REFORMS BY 2020/21

It is essential that people's human rights to receive care in the least restrictive setting, to give or withhold consent, to use advance decisions and to maintain family life are respected and that inspections assess the extent to which these rights are supported. Individuals deprived of their liberty under the Mental Health Act should be offered information, advocacy and support. In the light of rising rates of detention and the high and potentially inappropriate use of CTOs, highlighted by research published by Oxford University in 2013, there is a strong case for considering whether the current legislative framework strikes the right balance between risk and consent. This should include consideration of how mental capacity legislation should be applied in the use of the Mental Health Act to detain a person for compulsory treatment. This is a fundamental aspect of ensuring parity between mental and physical health.

The whole NHS plays a role in preventing mental health problems and caring for people who suffer them. The inspection system should be updated to ensure it covers all aspects of mental health provision in all settings, and all physical and mental health pathways of care.

For children and young people, we support the recommendation in 'Future in Mind' that the CQC should work with Ofsted to develop a joint, cross-inspectorate view of how health, education and social care services are working together to improve their mental health.

In July 2015, the Secretary of State for Health announced the creation of a new Healthcare Safety Investigation Branch (HSIB). The Branch will be established from April 2016 and will provide support and guidance to NHS organisations on investigations, as well as carrying out certain investigations itself. It will also conduct national investigations into safety incidents and act as an exemplar. It will focus on incidents that signal systemic or apparently intractable risks within the local health care system. The Department of Health should ensure that the scope of the HSIB includes deaths from all causes in inpatient mental health settings and that there is independent scrutiny of the quality of investigation, local and national trends, and evidence that learning is resulting in service improvement.

Recommendation 51: The Department of Health should work with a wide range of stakeholders to review whether the Mental Health Act (and relevant Code of Practice) in its current form should be revised in parts, to ensure stronger protection of people's autonomy, and greater scrutiny and protection where the views of a individuals with mental capacity to make healthcare decisions may be overridden to enforce treatment against their will.

Recommendation 52: The Department of Health should carry out a review of existing regulations of the Health and Social Care Act to identify disparities and gaps between provisions relating to physical and mental health services. This should include considering how to ensure that existing regulations extend rights equally to people experiencing mental health problems (e.g. to types of intervention that are mandated, to access to care within maximum waiting times).

Recommendation 53: Within its strategy for 2016–2020, the CQC should set out how it will strengthen its approach to regulating and inspecting NHS-funded services to include mental health as part of its planned approach to assessing the quality of care along pathways and in population groups.

Recommendation 54: The Department of Health should consider how to introduce the regulation of psychological therapy services, which are not currently inspected unless they are provided within secondary mental health services.

Recommendation 55: The CQC should work with Ofsted, Her Majesty's Inspectorate of Constabulary and Her Majesty's Inspectorate of Probation to undertake a Joint Targeted Area Inspection to assess how the health, education and social care systems are working together to improve children and young people's mental health outcomes.

Recommendation 56: The Department of Health should ensure that the scope of the Healthcare Safety Investigation Branch includes deaths from all causes in inpatient mental health settings and that there is independent scrutiny of the quality of investigation, analysis of local and national trends, and evidence that learning is resulting in service improvement.

Recommendation 57: NHS Improvement and NHS England, with support from PHE, should identify what steps services should take to ensure that all deaths by suicide across NHS-funded mental health settings, including out-of-area placements, are learned from, to prevent repeat events. This should build on insights through learning from never events, serious incident investigations and human factors approaches. The CQC should then embed this information into its inspection regime.

CHAPTER EIGHT:

LEADERSHIP INSIDE THE NHS, ACROSS GOVERNMENT AND IN WIDER SOCIETY

We have recommended an ambitious but deliverable strategy for mental health to realise improvements in prevention, access, outcomes and experience, backed by a strong clinical and economic case for investment. Implementing it will require robust leadership.

We commissioned a review by the Centre for Mental Health which identified 12 key elements necessary for the successful implementation of our vision:

1. **Leadership**: Effective national and local leadership is vital.
2. **Focus**: Strategies with a clear narrative and a set of widely supported, prioritised action points are more likely to succeed.
3. **Funding**: Funding for change and the associated double running costs is particularly important.
4. **Incentives**: Effective mental health strategies have benefited from close alignment with the incentives used in mainstream health policy.
5. **Workforce**: The most important changes are often the least amenable to policy-making and depend on the motivation of staff.
6. **Scrutiny**: Visible accountability for achieving a strategy's goals is essential to sustain implementation.
7. **Public opinion**: Strategies that enjoy support from the public and professionals are more likely to be implemented well.
8. **Partnerships**: Mental health policy relies on organisations working together.
9. Implementation: Robust, stable and supportive implementation infrastructure is vital.
10. **Innovation**: Policy cannot stand still but needs to facilitate innovation.
11. **Management**: Good quality programme and project management is essential.
12. **Time**: Changing practice takes longer than policymakers think. Policies need time to be implemented effectively.

Building on this evidence, a robust governance framework should be put in place to implement a 5-year programme to transform mental health care in

England. This strategy should be refreshed in 2019/20 in the light of new data that will emerge.

The key elements should be:

- **Establishing NHS England as the lead ALB** with responsibility for overall delivery of the strategy, led by the appointment of a new Senior Responsible Officer.
- **Embedding co-production** within the design and delivery of the programme, through the involvement of those with experience of mental health services and the organisations that represent them. This should include creating an independent external advisory board to provide independent scrutiny and challenge to the programme.
- **Establishing a new cross-ALB programme board** as a single coherent governance structure for delivering the strategy at a senior operational level, including defining the best approaches for local delivery.
- **Appointing an equalities champion,** with a specific remit to tackle mental health inequalities across the health system and through cross-government action.
- **Ensuring the necessary level of resource** within the national team overseeing day-to-day implementation.

The Department of Health, Cabinet Office and NHS England should put in place clear mechanisms for ensuring that the cross-government recommendations made in this report are implemented in full, and support continued action to combat stigma and discrimination in our society.

The Independent Commission on Acute Adult Psychiatric Care, established and supported by the Royal College of Psychiatrists, makes a recommendation that a Patients and Carers Race Equality Standard should be piloted in mental health. This should be given full consideration as quickly as possible as part of the remit of the new equalities champion.

Without additional investment it will not be possible to implement this strategy and deliver much-needed improvements to people's lives, as well as savings to the public purse. Funding is required in priority areas to help put the essential building blocks in place to improve the system over the long-term and to increase access to proven interventions that improve outcomes and deliver a return. We have identified that a minimum of £1 billion should be available in 2020/21. There should be a clear message that there is an expectation that more people are able to access NICE-evidenced services and that levels of investment in mental health should reflect this, across primary care, acute and mental health systems. Expenditure on mental health should be fully transparent.

Our proposals for investment are primarily targeted at expanding access to evidence-based care and scaling up effective programmes of work, supported by system reforms that are already happening and where the NHS can expand workforce capacity relatively quickly.

However, the Taskforce recognises the reality that reinvesting in services, planning for and recruiting into workforces that in many cases have been depleted in recent years, and initiating the essential system reforms required to support service expansion and transformation (e.g. relating to data and financial incentives) takes time.

Our proposals therefore focus on consolidating and expanding programmes for children and young people, for perinatal care and for Early Intervention in Psychosis 2016/17, in parallel to laying the ground for wider investment across the full range of priorities for action from 2017/18 onwards.

Securing new investment and realising the associated savings will require commissioners and providers, nationally and locally, to demonstrate that they are delivering high quality care and value for money within their budgets. This means implementing evidence-based standards, supporting quality improvement, improving data on outcomes and spend, a strong commitment to transparency, and integrating services at every level to meet the needs of their population. The transformation programme for Improving Access to Psychological Therapies for Children and Young People is a good example of how this can work. To make best use of new investment and ensure savings will materialise on the ground NHS England must also begin work now with ALB partners and local areas to trial new models of implementation.

We know that the scale of unmet mental health need is significant – hundreds of thousands of people go untreated each year at a cost of billions of pounds to our society and the economy. This investment would, however, make a start in plugging that gap, building on £1.4 billion of new funding over five years for children and young people’s and perinatal mental health last year, including additional funding for eating disorders.

Mental health must remain a priority in a challenging financial climate for the NHS in the next five years, which is why we have set out specific recommendations to ensure that there is proper transparency and accountability for how money is spent. At a minimum, from 2016/17 we expect CCGs to be able to demonstrate how they will increase investment in mental health services in line with their overall increase in allocation each year or in line with the growth in recurrent programme expenditure.

Recommendation 58: By no later than Summer 2016, NHS England, the Department of Health and the Cabinet Office should confirm what governance arrangements will be put in place to support the delivery of this strategy. This should include arrangements for reporting publicly on how progress is being made against recommendations for the rest of government and wider system partners, and the appointment of a new equalities champion for mental health to drive change.

ANNEX A:

PRINCIPLES UNDERPINNING PAYMENT APPROACHES IN MENTAL HEALTH

1. There must be no more unaccountable block contracts for mental health.

2. Providers should never entirely be rewarded for providing a number of days of care within a particular setting, but instead be rewarded for delivering whole pathways of care with achievement of defined outcomes or meeting local population need, as appropriate.

3. Both national and local outcome measures should be used as part of the payment system, these should be co-produced and developed by all stakeholders with a leading role taken by people with lived experience of mental ill health (and their families).

4. Where integrated care is needed, payment should similarly be integrated. For example, for urgent and emergency mental health care, the payment approach should be embedded within the wider urgent and emergency care payment approach, and payment for mental health care within physical care pathways should be similarly integrated.

5. Payment approaches should include access standards, where these are developed, to drive achievement of improved access to timely, evidence-based care with routine outcome measurement.

6. Payment approaches should be developed with experts-by-experience, reward engagement and delivery of access to excellent care for particular groups, where this is appropriate. This may include BAME populations and people with co-morbidities, such as substance misuse or diabetes.

7. Outcomes should be holistic and reward collaborative working across the system (e.g. stable housing, employment, social and physical health outcomes).

8. Payment systems must promote transparency and increased provision of high quality, relevant data that can drive improvement.

9. Payment systems should support improved productivity, value, efficiency and reduced costs, where possible.

10. Payment systems should support pathways through services, rewarding and incentivising step down to lower-intensity settings and a focus on care in the least restrictive setting. They should aim to reduce avoidable crises, admission and detentions, while protecting against any misalignment of incentives that might give rise to cherry-picking or other risks that might impact negatively upon those people with mental health problems who are ‘hardest to reach’.

11. National guidance should support commissioners to commission effectively using appropriate payment approaches.

12. Additional support should be provided to commissioners to build leadership, capacity and capability in commissioning services, including for the use of new payment approaches that will necessarily require new skills and competencies.

ANNEX B:

FULL RECOMMENDATIONS

Recommendations are listed by lead or joint lead agency for the NHS arms-length bodies

NHS ENGLAND	Future in Mind	NHS England should continue to work with HEE, PHE, Government and other key partners to resource and implement Future in Mind, building on the 2015/16 Local Transformation Plans and going further to drive system-wide transformation of the local offer to children and young people so that we secure measurable improvements in their mental health within the next four years. This must include helping at least 70,000 more children and young people each year to access high-quality mental health care when they need it by 2020/21. The CYP Local Transformation Plans should be refreshed and integrated into the forthcoming Sustainability and Transformation Plans (STPs), which cover all health and care in the local geography, and should include evidence about how local areas are ensuring a joined up approach that is consistent with the existing statutory framework for children and young people.
	Access standards and care pathways	By 2020/21, NHS England should complete work with ALB partners to develop and publish a clear and comprehensive set of care pathways, with accompanying quality standards and guidance, for the full range of mental health conditions based on the timetable set out in this report. These standards should incorporate relevant physical health care interventions and the principles of coproduced care planning, balancing clinical and non-clinical outcomes (such as improved wellbeing and employment). Implementation should be supported by: • Use of available levers and incentives to enable the delivery of the new standards, including the development of aligned payment models (NHS England and NHS Improvement) • Alignment of approaches to mental health provider regulation (NHS Improvement and CQC) • Comprehensive workforce development programmes to ensure that the right staff with the right skills are available to deliver care in line with NICE recommendations as the norm (HEE) • Ensuring that the relevant public health expertise informs the development of the new standards and that they are aligned with the new co-existing mental health and alcohol and/or drug misuse services guidance being developed for commissioners and providers of alcohol and/or drug misuse services. (PHE)

NHS ENGLAND	Perinatal mental healthcare	NHS England should invest to ensure that by 2020/21 at least 30,000 more women each year access evidence-based specialist mental health care during the perinatal period. This should include access to psychological therapies and the right range of specialist community or inpatient care so that comprehensive, high-quality services are in place across England.
	Psychological therapies for people with long term conditions	NHS England should invest to increase access to integrated evidence-based psychological therapies for an additional 600,000 adults with anxiety and depression each year by 2020/21 (resulting in at least 350,000 completing treatment), with a focus on people living with long-term physical health conditions and supporting people into employment. There must also be investment to increase access to psychological therapies for people with psychosis, bipolar disorder and personality disorder.
	Employment support	By 2020/21, NHS England and the Joint Unit for Work and Health should ensure that up to 29,000 more people per year living with mental health problems should be supported to find or stay in work through increasing access to psychological therapies for common mental health problems (see above) and doubling the reach of Individual Placement and Support (IPS). NHS England should seek to match this investment in IPS by exploring a Social Impact Bond or other social finance options.
	Early Intervention in Psychosis	NHS England should ensure that by April 2016 50 per cent of people experiencing a first episode of psychosis have access to a NICE–approved care package within two weeks of referral, rising to at least 60 per cent by 2020/21.
	Crisis services	By 2020/21, NHS England should expand Crisis Resolution and Home Treatment Teams (CRHTTs) across England to ensure that a 24/7 community-based mental health crisis response is available in all areas and that these teams are adequately resourced to offer intensive home treatment as an alternative to an acute inpatient admission. For children and young people, an equivalent model of care should be developed within this expansion programme.
	Acute liaison	By 2020/21 no acute hospital should be without all-age mental health liaison services in emergency departments and inpatient wards, and at least 50 per cent of acute hospitals should be meeting the ‘core 24’ service standard as a minimum.

NHS ENGLAND	Least restrictive acute care	In 2016, NHS England and relevant partners should set out how they will ensure that standards – co-produced with experts by experience, clinicians, housing and social care leads – are introduced for acute care services over the next five years. Integral to the standards should be the expectation that acute mental health care is provided in the least restrictive manner and as close to home as possible, with the practice of sending people out of area for acute inpatient care due to local acute bed pressures eliminated entirely by no later than 2020/21. Plans for introduction of the standards should form part of a full response to the Independent Commission on Acute Adult Psychiatric Care, established and supported by the Royal College of Psychiatrists, by no later than end 2016/17. NHS England and NHS Improvement should also ensure that use of the Mental Health Act is closely monitored at both local and national level, and rates of detention are reduced by 2020/21 through the provision of earlier intervention. Plans should include specific actions to substantially reduce Mental Health Act detentions and targeted work should be undertaken to reduce the current significant over-representation of BAME and any other disadvantaged groups in acute care.
	Secure care pathway	NHS England should lead a comprehensive programme of work to increase access to high quality care that prevents avoidable admissions and supports recovery and ‘step down’ for people of all ages who have severe mental health problems and significant risk or safety issues in the least restrictive setting, as close to home as possible. This should seek to address existing fragmented pathways in secure care, increase provision of community based services such as residential rehabilitation, supported housing and forensic or assertive outreach teams and identify new co-commissioning, funding and service models. This work should also tackle inequalities for groups shown to be over-represented in detentions and lengthy stays, and seek to ensure that out of area placements are substantially reduced. The programme should identify where and how efficiencies could be realised within the system and reinvested, and include recommendations on the wider reforms required to make this happen, including changes to legal processes. NHS England should also roll out the proven model of teams delivering community forensic CAMHS and complex need services nationally from 2016.
	Using and sharing data	By 2020/21, NHS England and NHS Improvement should work with the HSCIC and with Government to ensure rapid using and sharing of data with other agencies. The Department of Health should hold the HSCIC to account for its performance, and consult to set minimum service expectations for turning around new datasets or changes to existing datasets by no later than summer 2016.
	Vanguards	MCP, PACS, UEC vanguards and the Integrated Personalised Commissioning programme should be supported to ensure that the inclusion of payment for routine integrated care adequately reflects the mental health needs of people with long-term physical health conditions within new care model programmes. Vanguard sites should also provide greater access to personal budgets for people of all ages, including children and young people who have multiple and complex needs, to provide more choice and control over how and when they access different services.

NHS ENGLAND	Physical health outcomes in people with mental illness	NHS England should undertake work to define a quantified national reduction in premature mortality among people with severe mental illness, and an operational plan to begin achieving it from 2017/18. NHS England should also lead work to ensure that by 2020/21, 280,000 more people living with severe mental illness have their physical health needs met by increasing early detection and expanding access to evidence-based physical care assessment and intervention. This will involve developing, evaluating and implementing models of primary care whereby GPs and practice nurses take responsibility for delivering the full suite of physical care screenings, outreach, carer training and onward interventions or referrals, in line with NICE guidelines. This model should include outreach workers or carer training to support people to access primary care because many people with psychosis struggle to access services, and give GPs and practice nurses the training and time they need to deliver NICE-concordant screening and care.
	Older age specialist services	NHS England should ensure that people being supported in specialist older-age acute physical health services have access to liaison mental health teams – including expertise in psychiatry of older adults – as part of their package of care, incentivised through the introduction of a new national CQUIN or alternative incentive payments and embedded through the vanguard programmes.
	Trialling population based budgets	NHS England should ensure that by April 2017 population-based budgets are in place which give CCGs or other local partners the opportunity to collaboratively commission the majority of specialised services across the life course. In 2016/17 NHS England should also trial new models through a Vanguard programme that allow secondary providers of these services to manage care budgets for tertiary (specialised) mental health services to improve outcomes and reduce out of area placements. We recommend testing this at scale, with a particular focus on secure care commissioning, perinatal and specialised CAMHS services.
	Co-production evaluation	NHS England should work with NHS Improvement to run pilots to develop evidence based approaches to co-production in commissioning by April 2018.
	CCG inequalities – funding	NHS England should disaggregate the inequalities adjustment from the baseline funding allocation for CCGs and Primary Care, making the value of this adjustment more visible and requiring areas to publicly report on how they are addressing unmet mental health need and mental health inequalities.
	NHS staff mental health	NHS England should ensure current health and wellbeing support to NHS organisations extends to include good practice in the management of mental health in the workplace, and provision of occupational mental health expertise and effective workplace interventions from 2016 onwards.

NHS ENGLAND	Navigators	NHS England and NHS Improvement should encourage providers to ensure that 'navigators' are available to people who need specialist care from diagnosis onwards, to guide them through options for their care and ensure they receive appropriate information and support. In parallel, NHS England and HEE should work with voluntary and community sector organisations, experts-by-experience and carers to develop and evaluate the role of 'navigators' in enabling more people-centred care to be provided.
	Trialling acute care models or 16-25s	NHS England should work with CCGs, local authorities and other partners to develop and trial a new model of acute inpatient care for young adults aged 16–25 in 2016, working with Vanguard sites. This should evaluate: developmentally and age-appropriate inpatient services for this group; supporting young people in an environment that maximises opportunities for rehabilitation and return to education, training or employment; viewing the young person within their social context; and enlisting the support of families or carers. This should build on the existing trials of new models of 'transitional' services for those aged 0–25.
	NHS staff awareness	NHS England should develop and introduce measures of staff awareness and confidence in dealing with mental health into annual NHS staff surveys across all settings.
	Staff health & wellbeing	NHS England should introduce a CQUIN or alternative incentive payment relating to NHS staff health and wellbeing under the NHS Standard Contract by 2017.
	Data stocktake	NHS England and the HSCIC should work to identify unnecessary data collection requirements, and then engage with NHS Improvement to prioritise persistent non-compliance in data collection and submission to the MHSDS, and take regulatory action where necessary. For the most important data items (including inequalities data), commissioners should use NHS standard contract sanctions (financial penalty) for a data breach where there is persistent non-return of data. Commissioners should be required to use national data flows where they exist and not place undue pressure on providers by asking for local data that duplicates national data.
	Payment system	NHS England and NHS Improvement should together lead on costing, developing and introducing a revised payment system by 2017/18 to drive the whole system to improve outcomes that are of value to people with mental health problems and encourage local health economies to take action in line with the aims of this strategy. This approach should be put in place for children and young people's services as soon as possible.
	Governance	NHS England, the Department of Health and the Cabinet Office should confirm what governance arrangements will be put in place to support the delivery of this strategy. This should include arrangements for reporting publicly on how progress is being made against recommendations for the rest of government and wider system partners.

Public Health England	Mental Health Intelligence Network	During 2016 NHS England and Public Health England should set a clear plan to develop and support the Mental Health Intelligence Network over the next five years, so that it supports data linkage across public agencies, effective commissioning and the implementation of new clinical pathways and standards as they come online.
	Preventing poor physical health outcomes	Public Health England should prioritise ensuring that people with mental health problems who are at greater risk of poor physical health get access to prevention and screening programmes. This includes primary and secondary prevention through screening and NHS Health Checks, as well as interventions for physical activity, obesity, diabetes, heart disease, cancer and access to ‘stop smoking’ services. As part of this, NHS England and PHE should support all mental health inpatient units and facilities (for adults, children and young people) to be smoke-free by 2018.
	Preventing mental ill health	PHE should develop a national Prevention Concordat programme that will support all Health and Wellbeing Boards (along with CCGs) to put in place updated JSNA and joint prevention plans that include mental health and comorbid alcohol and drug misuse, parenting programmes, and housing, by no later than 2017.
Care Quality Commission	Integrated regulation of CYP services	The CQC should work with Ofsted, Her Majesty’s Inspectorate of Constabulary and Her Majesty’s Inspectorate of Probation to undertake a Joint Targeted Area Inspection to assess how the health, education and social care systems are working together to improve children and young people’s mental health outcomes.
	Quality inspection across settings	The CQC should develop regulation and inspection of NHS-funded services to include mental health as part of its planned approach to assessing the quality of care along pathways and in population groups, beyond the inspection of providers. Within its strategy for 2016–2020, the CQC should also set out how it will strengthen its approach to: • How it inspects primary medical services, acute and adult social care services, so that it assesses whether these services are providing high-quality care for people with mental health problems • Inspect providers on the quality of co-production in individual care planning, carer involvement and in working in partnership with communities to develop and improve mental health services (drawing on good practice such as the 4PI principles) • Ensure that, from 2016, inspections of all specialist mental health services reflect the extent to which the provider ensures that people have an outcomes-focused recovery path that includes discharge and future planning and is integrated with other services, incorporating housing and other social needs · Ensure (with support from the Department of Health) that data captured about experience of inpatient mental health services is represented in a form which allows comparison and improvement monitoring at national level • Incorporates good practice in information sharing with other providers and with mental health carers, to address complex issues relating to how patient confidentiality rules apply in the care of people with mental health problems.

NHS Improvement	Learning from deaths by suicide	NHS Improvement and NHS England, with support from Public Health England, should identify what steps services should take to ensure that all deaths by suicide across NHS-funded mental health settings, including out-of-area placements are learned from to prevent repeat events. This should build on insights through learning from never events, serious incident investigations and human factors approaches. The CQC should then embed this information into its inspection regime.
Health Education England	Workforce planning and development across settings	HEE should work with NHS England, PHE, professional bodies, charities, experts-by-experience and others to develop a costed, multi-disciplinary workforce strategy for the future shape and skill mix of the workforce required to deliver both this strategy and the workforce recommendations set out in Future in Mind. This review should address training needs for both new and existing NHS-funded staff and should report by no later than the end of 2016. This workforce strategy should include: • Clear projections for required staff numbers to 2020/21 and what action will be taken to plug any gaps • Core training in basic mental health awareness and knowledge, understanding of mental health law, public mental health, compassion and communication skills • For professions involved in the care and support of people with mental health problems, tailored curricula with competencies in dealing with the common physical health problems people may present with, shared decision-making, mental health prevention (including suicide), empowering people to understand their own strengths and self-manage, carer involvement and information sharing. Drawing on the best available evidence, this should also ensure that professionals are equipped to provide age-appropriate care and reduce inequalities. HEE and PHE should develop an action plan so that by 2020/21 validated courses are available in mental health promotion and prevention for the public health workforce (including primary care).
	Prescribing standards	HEE should work with the Academy of Medical Royal Colleges to develop standards for all prescribing health professionals that include discussion of the risks and benefits of medication, take into account people's personal preferences, include preventative physical health support and the provision of accessible information to support informed decision-making. This should be completed in collaboration with relevant stakeholders by April 2017 and subject to regular review.

RECOMMENDATIONS FOR GOVERNMENT

Cabinet office	Co-morbid mental health and substance misuse problems	The Cabinet Office should ensure that the new Life Chances Fund of up to £30m for outcomes-based interventions to tackle alcoholism and drug addiction requires local areas to demonstrate how they will integrate assessment, care and support to people with co-morbid substance misuse and mental health problems, and make a funding contribution themselves. It should also be clear about the funding contribution required from local commissioners to pay for the outcomes that are being sought.
Department of Health	Research	The UK should aspire to be a world leader in the development and application of new mental health research. The Department of Health, working with all relevant parts of government, the NHS ALBs, research charities, independent experts, industry and experts-by-experience, should publish a report one year from now, setting out a 10-year strategy for mental health research. This should include a co-ordinated plan for strengthening and developing the research pipeline on identified priorities, and promoting implementation of research evidence.
	Equalities	The Department of Health should appoint a new equalities champion with a specific remit to tackle health inequalities amongst people with mental health problems and carers across the health and social care system and through cross-government action. This role should include responsibility for advising on operational activity within the NHS to reduce discrimination for people found to be at particular risk, including but not limited to those with characteristics protected by the Equalities Act. The Independent Commission on Acute Adult Psychiatric Care, established and supported by the Royal College of Psychiatrists, makes a recommendation that a Patients and Carers Race Equality Standard should be piloted in mental health and this should form part of the remit of the new role-holder.
	Suicide prevention	The Department of Health, PHE and NHS England should support all local areas to have multi-agency suicide prevention plans in place by 2017, contributing to a 10 per cent reduction in suicide nationally. These plans should set out targeted actions in line with the National Suicide Prevention Strategy and new evidence around suicide, and include a strong focus on primary care, alcohol and drug misuse. Each plan should demonstrate how areas will implement evidence-based preventative interventions that target high-risk locations and support high-risk groups (including young people who self-harm) within their population, drawing on localised real time data. Updates should be provided in the Department of Health's annual report on suicide.
	Mental Health Act	The Department of Health should work with a wide range of stakeholders to review whether the Mental Health Act (and relevant Code of Practice) in its current form should be revised in parts, to ensure stronger protection of people's autonomy, and greater scrutiny and protection where the views of individuals with mental capacity to make healthcare decisions may be overridden to enforce treatment against their will.

Department of Health	Social work	The Department of Health should continue to support the expansion of programmes that train people to qualify as social workers and contribute to ensuring the workforce is ready to provide high quality social work services in mental health. This should include expanding ‘Think Ahead’ to provide at least an additional 300 places.
	Supported housing	The Department of Health, Communities and Local Government, NHS England, HM-Treasury and other agencies should work with local authorities to build the evidence base for specialist housing support for vulnerable people with mental health problems and explore the case for using NHS land to make more supported housing available for this group.
	Health and Justice care pathway	The Ministry of Justice, Home Office, Department of Health, NHS England and PHE should work together to develop a complete health and justice pathway to deliver integrated health and justice interventions in the least restrictive setting, appropriate to the crime which has been committed. This should build on the national roll out of Liaison and Diversion schemes (including for children and young people) across England by 2020/21 and the increased uptake of Mental Health Treatment Requirements (diversion through court order to access community based treatment) as part of community sentences for everyone who can benefit from them. It should also improve mental health services in prison and the interface with the secure care system, with continuity of care on release, to support offenders to return to the community.
	Data improvement	The Department of Health, NHS England, PHE and the HSCIC should develop a 5-year plan to: address the need for substantially improved data on prevention, prevalence, access, quality, outcomes and spend across mental health services; set out responsibilities for each agency in providing the necessary legal, commissioning, and quality and safety information required; design and develop new datasets, linking physical health, mental health, social care and employment datasets, while ensuring that information governance adequately protects people’s rights; include mental health measures in all physical care datasets, including emergency care. The HSCIC should act as a data system leader and set new minimum service expectations for turning around new datasets or changes to existing datasets. The Department of Health, NHS England, HSCIC and NHS Improvement should publish a summary progress report by the end of 2016 setting out how the specific actions on data, information sharing and digital capability identified in this report and the National Information Board’s Strategy are being implemented.
	Children and Young People metrics	The Department of Health should develop national metrics to support improvements in children and young people’s mental health outcomes, drawing on data sources from across the whole system, including NHS, public health, local authority children’s services and education, to report with proposals by 2017.

Department of Health	Greater transparency	The Department of Health, HSCIC and MyNHS, working with NHS England, should improve transparency in data to promote choice, efficiency, access and quality in mental health care, ensuring that all NHS-commissioned mental health data are transparent (including where data quality is poor) to drive improvements in services. The CCG Performance and Assessment Framework should include a robust basket of indicators to provide a clear picture of the quality of commissioning for mental health. To complement this, NHS England should lead work on producing a Mental Health FYFV Dashboard by the summer of 2016 that identifies metrics for monitoring key performance and outcomes data that will allow us to hold national and local bodies to account for implementing this strategy. The Dashboard should include health and social outcomes including employment and settled housing outcomes for people with mental health problems.
	Prevalence surveys	The Department of Health should commission regular prevalence surveys for children, young people and adults of all ages that are updated not less than every 7 years.
	CCG transparency	The Department of Health and NHS England should require CCGs to publish data on levels of mental health spend in their Annual Report and Accounts, by condition and per capita, including for Children and Adolescent Mental Health Services, from 2017/18 onwards. They should require CCGs to report on investment in mental health to demonstrate the commitment that commissioners must continue to increase investment in mental health services each year at a level which at least matches their overall allocation increase. For children and young people, this should be broken down initially into spend in the community, on emergency, urgent and routine treatment, and for inpatient care.
	Parity for mental health in Health & Social Care Act regulations	The Department of Health should carry out a review of existing regulations of the Health and Social Care Act to identify disparities and gaps between provisions relating to physical and mental health services. This should include considering how to ensure that existing regulations extend rights equally to people experiencing mental health problems (e.g. to types of intervention that are mandated or to access care within maximum waiting times).
	Deaths in inpatient settings	The Department of Health should ensure that the scope of the new Healthcare Safety Investigation Branch includes a clear focus on deaths from all causes in inpatient mental health settings, including independent scrutiny of the quality of investigation, analysis of local and national trends, and evidence that learning is resulting in service improvement. This should include the involvement of families, and build on the models and experiences of the Independent Police Complaints Commission and the Prisons and Probation Ombudsman. The Department should also work with the CQC to establish a methodology for inspecting the quality of learning from all deaths in inpatient mental health services, including introducing greater transparency around the cause of deaths within each provider.

Department of Health	Challenging stigma	The Department of Health should work with PHE to continue to support proven behaviour change interventions, such as Time to Change, and to establish Mental Health Champions in each community, to contribute to improving attitudes to mental health by at least a further 5 per cent by 2020/21.
	Innovation fund for devolved areas	The Department of Health and the Department for Work and Pensions, working with NHS England and PHE, should identify how the £40 million innovation fund announced at the Spending Review and other investment streams should be used to support devolved areas to jointly commission more services that have been proven to improve mental health and employment outcomes, and test how the principles of these services could be applied to other population groups and new funding mechanisms (e.g. social finance).
	Digital	The Department of Health, through the National Information Board, should ensure there is sufficient investment in the necessary digital infrastructure to realise the priorities identified in this strategy. Each ALB should optimise the use of digital channels to communicate key messages and make services more readily available online, where appropriate, drawing on user insight. Building on trial findings, NHS England should expand work on NHS Choices to raise awareness and direct people to effective digital mental health products by integrating them into the website and promoting them through social marketing channels from 2016 onwards.
	New GPs	The Department of Health and NHS England should work with the RCGP and HEE to ensure that by 2020/21 all GPs, including the 5,000 joining the workforce by 2020/21, receive core mental health training, and to develop a new role of GPs with an extended Scope of Practice (GPwER) in Mental Health, with at least 700 in practice within 5 years.
	Regulation of psychological therapies	The Department of Health should consider how to introduce the regulation of psychological therapy services, which are not currently inspected unless provided within secondary mental health services.
	Better Care Fund	To drive and scale improvements in integration, the Department of Health and relevant partners should ensure that future updates to the Better Care Fund include mental health. This might include making an element of payment for outcomes contingent on reducing acute admission through requiring all hospitals to comply with Crisis Care Concordat and NICE standards on liaison and crisis mental health care.
	Summary Care Records	The Department of Health and HSCIC should advocate adoption of data-rich Summary Care Records that include vital mental health information, where individuals consent for information to be shared, by 2016/17.

Department for Work & Pensions	Employment support	The Department for Work and Pensions should ensure that when it tenders the Health and Work Programme it directs funds currently used to support people on Employment Support Allowance to commission evidence-based health-led interventions that are proven to deliver improved employment outcomes – as well as improved health outcomes – at a greater rate than under current Work Programme contracts. The Department of Work and Pensions should also invest to ensure that qualified employment advisers are fully integrated into expanded psychological therapies services.
	Housing Benefit cap	The Department of Work and Pensions should, based on the outcome of the "Supported Housing" review in relation to the proposed Housing Benefit cap to Local Housing Allowance levels, use the evidence to ensure the right levels of protection are in place for people with mental health problems who require specialist supported housing.
Department for Education / Department of Health / Department for Work and Pensions	Parenting programmes and support for children with complex needs	The Departments of Education and Health should establish an expert group to examine the needs of children who are particularly vulnerable to developing mental health problems and how their needs should best be met, including through the provision of personalised budgets. The Government should also review the best way to ensure that the significant expansion of parenting programmes announced by the Prime Minister builds on the strong-evidence base that already exists and is integrated with Local Transformation Plans for Children and Young People's mental health services.
HEFCE	Research	HEFCE should review funding requirements and criteria for decision-making to support parity through the Research Excellence Framework and take action to ensure that clinical academics in mental health (including in psychiatry and neuroscience) are not disadvantaged relative to other areas of health research, starting in 2016/17.
ACRA	Inequalities and funding allocation formula	ACRA should review NHS funding allocation formulas, including the inequalities adjustment, to ensure it supports parity between physical and mental health in 2016/17. They should also be reviewed to ensure they correctly estimate the prevalence and incidence of conditions across the mental health spectrum. Membership of ACRA should be revisited with the specific goal of ensuring that mental health expertise is adequately represented across the disciplines involved, e.g. clinical, academic, policy and providers.

The Mental Health Taskforce

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THE WESTMINSTER COMMISSION ON AUTISM

A Spectrum of Obstacles

An Inquiry into Access to Healthcare for Autistic People

NCG NATIONAL CHILDREN'S GROUP

It is critical to improve access to healthcare for autistic people of all ages. This population have increased health risks and reduced life expectancy, yet face multiple obstacles to accessing the same healthcare that other population groups enjoy.

The knock-on effect of poor access to healthcare on physical and mental health, on employment and the economy, on quality of life and mortality, leads us to **request positive action now.**

July 2016

The Westminster Commission on Autism has been financed by the National Children's Group. The National Children's Group has been set up by the National Children's Centre to run initiatives such as this Commission. These initiatives seek to bring organisations together and find solutions to issues affecting the welfare of individuals and families. Historically a children's charity, the National Children's Centre now champions the welfare of children, families and older people. The Westminster Commission on Autism is interested in autism across all age groups.

This report follows a seven-month inquiry chaired by Barry Sheerman MP.

The report has been written by Emily Christou, National Strategy Coordinator, National Children's Group with help from the Commission Members.

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Terminology

- **Autism** is used in this report as a term encompassing all Autistic Spectrum Conditions (including Asperger's Syndrome). Autism is a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them[1].

- This report will refer to '**autistic people'**. The decision to use this phrase as opposed to 'people with autism' or 'people on the autistic spectrum' was taken following research which demonstrates that autistic people generally prefer this term[2].

- **Health** is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity[3].

- **Health care** refers to services provided to individuals or communities by health service providers for the purpose of promoting, maintaining, monitoring or restoring health[4].

- **Neuro-typical** refers to those with normative neuro-development. I.e. those who do not have neurodevelopmental condition such as autism.

- **Obstacles** refer to problems or difficulties that prevent progress.

- **The Westminster Commission on Autism** is an independent, cross-party, cross-sector coalition of autistic individuals, parent-advocates, Parliamentarians and leaders from the autism 'sector'. The members have a commonality of purpose; to see the world become a more autism-friendly place.

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[1] Autism.org.uk. (2016). What is autism? - NAS. [online] Available at: http://www.autism.org.uk/about/what-is.aspx [Accessed 17 May 2016].
[2] Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., Pellicano, E. (2015). Which terms should be used to describe autism? Perspectives from the UK autism community. Autism. Available at: http://crae.ioe.ac.uk/post/130542870298/is-a-person-autistic-do-they-have-autism-or
[3] Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.
[4] who.int. (2004). A Glossary of Terms for Community Health Care and Services for Older People. [online] Available at: http://www.who.int/kobe_centre/ageing/ahp_vol5_glossary.pdf [Accessed 17 May 2016].

The Members of the Commission

Parliamentarians:
Barry Sheerman MP (Chair)
Rt Hon. Cheryl Gillan MP (Chair of the All-Party Parliamentary Group on Autism)
Steve McCabe MP
The Baroness Uddin*
Tim Loughton MP

Autistic Self-Advocates:
Helen Ellis – Autism Public Speaker
Dr Damian Milton* - Researcher, London South Bank University
Craig Kennady* - Autism Campaigner
Jonathan Andrews – Equality Improvement Champion, Mind and Chair of Youth Council, Ambitious About Autism
Susan Dunne - Author

Charities and Service Providers:
Ambitious About Autism
Autism Alliance UK
Autism Plus
Autism West Midlands
Autistica
Hesley Group
Hidden Impairment National Group
National Autistic Society
National Children's Group
North East Autism Society
Research Autism
The Giving Tree Foundation*

Individuals:
Dame Stephanie Shirley* – Founder of Autistica, Kingwood Trust, Prior's Court School, Autism Cymru and the National Autism Project
Dr Carole Buckley* – Clinical Champion for Autism at the Royal College of General Practitioners
Steven Michael OBE – Chair of the NHS Confederation Mental Health Network (now Ex-Chair)

Academics:
Professor Emily Simonoff - Professor of Child and Adolescent Psychiatry, King's College London and National Autism Project Strategy Board Member
Dr Liz Pellicano - Director of the Centre for Research in Autism and Education
Professor Nicola Martin* - Head of Research, Law and Social Sciences School LSBU
Richard Mills - Research Director, Research Autism
Professor Simon Baron Cohen FBA - Director of the Autism Research Centre, Professor of Developmental Psychopathology, University of Cambridge

*Also a parent-advocate.

Contents

Foreword

“Over the course of this inquiry, it has become clear to me that getting healthcare right for people on the autistic spectrum is critical.”

- Critical for equality; why should neuro-typical people have a wonderful NHS freely accessible to them but those on the spectrum have such a fight for the same quality service?
- Critical for living long lives; I was shocked to hear that a large, high-quality, Swedish study has shown that people on the autistic spectrum die an average of sixteen years prematurely. Getting healthcare right must be the first step to rectifying this inequality. The same study showed that those with autism and a learning disability have a life expectancy of 39. Such inequalities need to be mapped here in the UK and could show a similar pattern. If so, this has got to change.
- Critical for quality of life; autism is a complex condition with many associated co-occurring conditions. If we do not understand how to treat these co-occurring conditions, many may be left in poor health, unable to work and isolated from the society they so want to be a part of.
- Critical for employment; autism is estimated to cost the UK economy £32billion per annum[5]. This is more than cancer, stroke and heart disease combined. Much of this cost is due to loss of earnings yet many autistic people want to work and cannot find suitable employment. Some autistic people are living in poor physical or mental health and cannot work. If autistic people receive good physical and mental health care, have timely access to low level preventative support, are supported into employment and are embraced by the neuro-typical population, they can thrive.

This is not a critique of the NHS. This report seeks to highlight what good quality, person-centred healthcare, tailored to the needs of those on the autistic spectrum, can achieve. It is a call for ensuring equal access to quality healthcare for all on the autistic spectrum and to make this widespread and institutionalised.

If we fail to take immediate, sensible steps to improve access to healthcare for autistic people we may lose many more to unemployment, mental health issues, poor quality of life and even premature death.

This Commission has undertaken a thorough investigation of the issues and potential solutions. It has made six key recommendations approved by this strong coalition. We ask the Government to continue their commendable work in improving services for autistic people. We also ask them to listen to the autistic people, their families and the professionals who have voiced their ideas through this report and make changes to see lives improved.

Barry Sheerman MP

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[5] Knapp, M., Romeo, R. and Beecham, J. (2009). Economic cost of autism in the UK. Autism, 13(3), pp.317-336.

Easy Read Summary of Our Report

We want to make sure that autistic people live long and healthy lives.

Many autistic people live long lives but some do not.

The Government knows that they need to help autistic people live long and healthy lives. In 2009, a law was passed called the ‘Autism Act’. Because of this law, the Government now has an ‘autism strategy’.

The strategy is a very good start to meeting the needs of autistic people.

We think that health services still need to get better for autistic people. The Government should make some changes.

This is what we did and what we found out:

We have heard from lots of autistic people, families and carers, and autism professionals.

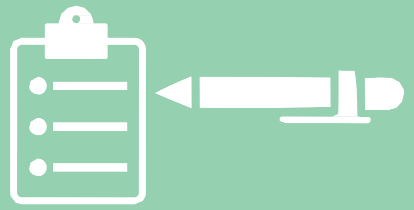
Some spoke to us on the telephone, others by email, some wrote to us and others filled in a survey.

This is what people told us:

Autistic people feel that health professionals do not always understand autism.

88% of the autistic people we spoke to said that they do not think health professionals understand their needs as an autistic person.

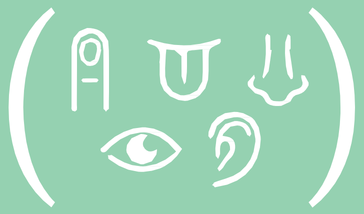
Autistic people do not always have people to help them access health services.



Doctors do not always keep a record of the autistic people using health services.

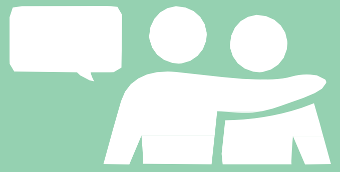
We think it is hard for professionals to understand autism because:

Every person on the autistic spectrum is different.



Autistic people often have sensitivity to lights, sounds, smells, tastes and touch. This means they can find it difficult to concentrate in hospitals or doctors surgeries.

Autistic people can find it very hard to tell the doctor what is wrong.



Autistic people do not always have someone to remind them to get help with their health.

There are some other things that make it difficult:

Autistic people often have other conditions such as ADHD or epilepsy. Doctors do not always understand these different conditions in autistic people.

Lots of autistic people also have a mental health condition. Health professionals do not always understand how to help an autistic person who has a mental health condition.

We have suggested 6 changes so that all autistic people can live long and healthy lives.

Things we think should change:

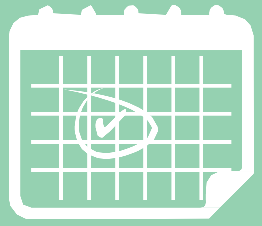
1

We think that the Care Quality Commission should make sure that health professionals are doing a good job for autistic people.

2

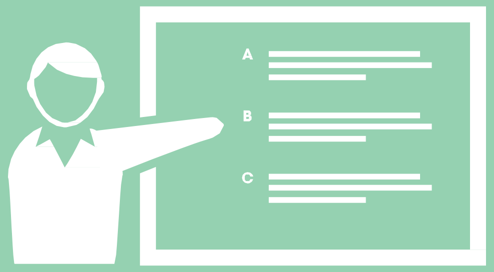
We think doctors should make a note on the computer for autistic patients.

This means that your doctor would know you are autistic and should make changes to meet your needs.



3

We think all autistic people should be offered to go to their doctor every year to have a health check.



4

We think that all health professionals should have autism training. NHS England should help to make training possible.

5

We think that the Government should make some money available. This money should be used to help autistic people understand what will happen at the doctor or hospital.

6

We think that NHS England should have an Autism Champion to lead on making changes for autistic people. We think that this would improve services for autistic people.

Executive Summary

According to our survey, 74% (n=497) of autistic, parent-advocate and professional respondents feel that autistic people receive 'worse' or 'much worse' healthcare than non-autistic people. Autistic people face significant risks to their health and can die unacceptably early[6]. But it does not have to be this way.

The passing of the Autism Act 2009[7] was an historic moment for the autistic community and has led to more focused attention on the issues affecting autistic people.

Following the Act, the Government has recognised the need to reduce the health gap for autistic people and included this in the 'Mandate to the NHS'. The Commission welcomes the Government's commitment to this issue. We have conducted a thorough investigation of the issues and consulted with over 900 autistic people, families and professionals. Our findings should be useful tools to help those trying to close the health gap.

Our evidence-gathering process has revealed a number of obstacles that autistic people encounter when accessing healthcare. These obstacles can be helped to be reduced by the implementation of our six recommendations.

The obstacles include (but are not limited to):

- Lack of training for health professionals and lack of strong accountability to ensure that health services meet the specific needs of the autistic population. 70% (n= 473) of our survey respondents chose training for healthcare professionals as the priority which would most improve access to healthcare for autistic people
- The lack of training leads to perceived poor understanding of autism and the feeling among autistic people that their health treatment is unsatisfactory
- Statistically, autism is largely 'invisible' in the health system as data collection is sparse. 76% (n= 241) of autistic people and parent-advocates told us that their General Practitioner (GP) does not make any reasonable adjustments for them or their autistic child. This is an indication that health professionals may not consistently identify autistic people and make accommodations for their needs
- Autistic people told us that they can struggle to identify changes in their health needs and seek appropriate help. This could be countered by monitoring the mental and physical health needs of the autistic population more closely. This could be achieved through Annual Health Checks
- Improvements in healthcare for autistic people can be complicated to make and this is exacerbated by a lack of leadership; NHS England does not have a National Clinical Director for autism nor a lead member of staff for autism
- Some autistic people may need assistance to access healthcare but many are socially isolated and lack support networks

This inquiry is timely but we have already seen too many autistic people living with poor physical and mental health and lost to premature death. This should spur us on to making important improvements now.

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[6] If you have concerns about the statement that autistic people IN Sweden have decreased life expectancy, please visit this website which gives an explanation. Many autistic people live long and healthy lives. http://www.autismeastmidlands.org.uk/information-about-report-autistica#

[7] Legislation.gov.uk. (2016). Autism Act 2009. [online] Available at: http://www.legislation.gov.uk/ukpga/2009/15/contents [Accessed 13 May 2016].

A large study, conducted in Sweden, has shown that on average autistic people die 16 years prematurely[8]. Research from other countries has also suggested that autistic people may be at risk of dying earlier. Yet in this country, the lack of data and research in this area means that we simply do not know the mortality risks of autistic people in England.

The timely use of appropriate, high-quality and person-centred healthcare can help ensure quality health for autistic people. However, we found that 74% (n=497) of all survey respondents think autistic people receive 'worse' or 'much worse' healthcare and 65% (n=440) think that health professionals 'rarely' or 'never' understand autism and how it affects someone's physical and mental health.

The statutory guidance associated with the Autism Act states that autism-awareness has to be included in all equality and diversity training for health and social care staff and ensure that both general awareness and specialist autism training is provided on an ongoing basis[9]. However, in the most recent self-assessment of progress against the strategy, only 29% of local areas rated themselves as 'green', meaning that training was available to all staff[10][11]. This suggests that many local areas are failing to comply fully with the Autism Act.

In addition, there is nothing in any of the NHS outcomes frameworks to measure outcomes for autistic people specifically. This is likely to mean that training in autism is not the priority it should be.

Even when healthcare staff have been trained, they still may be unable to identify autistic patients. This is, in part, due to inconsistent data collection and management. As a result, healthcare staff may not implement their training and reasonably adjust their services.

95% (n=302) of autistic survey respondents want GPs to have a note on their computer screen to tell them that the patient they are seeing is autistic and 94% (n=297) would be happy to be added to an anonymous database of autistic patients.

If services could consistently identify autistic patients, they may have a better chance at tailoring services to the needs of autistic patients and begin to reduce some of the risks to their health. This could be achieved through offering annual health checks to all autistic patients. Such checks have worked well for people with a learning disability in identifying unrecognised but treatable conditions[12]. Introduction of such checks for autistic people would need to be based on research evidence and be developed in consultation with the autistic community to ensure that they are effective.

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[8] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P. and Bolte, S. (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), pp.232-238. Available at: http://www.ncbi.nlm.nih.gov/pubmed/26541693

[9] Legislation.gov.uk. (2016). Autism Act 2009. [online] Available at: http://www.legislation.gov.uk/ukpga/2009/15/contents [Accessed 13 May 2016].

[10] Legislation.gov.uk. (2016). Autism Act 2009. [online] Available at: http://www.legislation.gov.uk/ukpga/2009/15/contents [Accessed 13 May 2016].

[11] Improvinghealthandlives.org.uk. (2016). Autism self-assessment 2014 :: Public Health England - Improving Health and Lives. [online] Available at: http://www.improvinghealthandlives.org.uk/publications/313914/Autism_self-assessment_2014 [Accessed 14 May 2016].

[12] Robertson, J., Roberts, H. and Emerson, E. (2010). Health Checks for People with Learning Disabilities: A Systematic Review of Evidence. [online] improvinghealthandlives.org.uk. Available at: https://www.improvinghealthandlives.org.uk/uploads/doc/vid_7646_IHAL2010-04HealthChecksSystemticReview.pdf [Accessed 15 May 2016].

An additional interlinked obstacle is the lack of leadership on autism within the health sector. There is no National Clinical Director for autism within NHS England. In contrast, there are National Clinical Directors for learning disability, dementia and mental health. There is an autism-lead in the Department of Health but there is no counterpart autism-lead at NHS England. It is challenging to drive real improvements for autistic people in the health sector without professionals who take responsibility for the issues and lead change. There are examples of committed individual healthcare professionals doing excellent work in the autism field. However, this is not the norm and is usually self-initiated.

The Care Quality Commission (CQC) do not ask autism specific questions in their healthcare inspections; 97% (n=748) of our survey respondents think that they should. Training for health professionals is not embedded and data on training take-up is not routinely collected. NHS England and other NHS bodies do not have titled autism-leaders. The ‘accountability’ mechanism for implementing the Autism Act is a Self-Assessment Framework (SAF) which is a useful tool. However, local authorities are responsible for the SAF and the main accountability mechanisms that the NHS pay attention to (e.g. NHS Outcomes Framework) do not have any measures on autism. This series of obstacles may hinder autistic people’s healthcare.

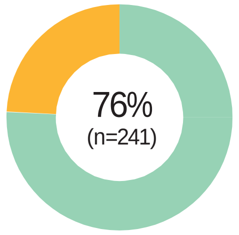
We have made six achievable and important recommendations to help the NHS fulfil the Government’s call to reduce the health gap for this population and reduce the obstacles.

It should be noted that as health and social care are devolved to the Welsh Government, Scottish Government and Northern Ireland Executive, this report and its recommendations are concerned with England.

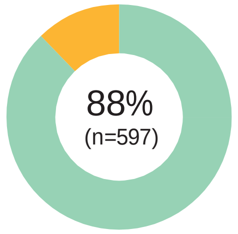
Summary of Recommendations

Recommendation One – Training:

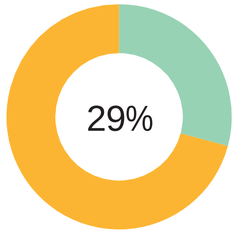
NHS England should issue a resource pack to assist Clinical Commissioning Groups (CCGs) in making sure training of all healthcare staff is embedded and data is collected on take-up; Secretary of State for Health to issue a letter instructing CCGs that they are obliged under the Autism Act’s statutory guidance, to follow the requirements on training; those in control of clinical curricula, including Health Education England, should ensure all commissioned undergraduate and postgraduate training includes autism-awareness.



of autistic and parent-advocate survey respondents said **their doctor does not make any changes to meet their (or their child’s) needs as an autistic person**;



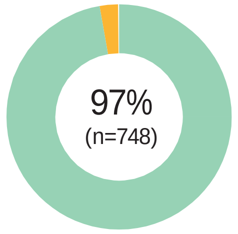
of all survey respondents **do not feel that health professionals understand the conditions which co-occur alongside autism**;



the Self-Assessment Framework shows only 29% **of local areas rated themselves ‘green’ for having training available to all staff**; a decrease on statistics from 2013 when 38% rated themselves green[13].

Recommendation Two - Inspection:

The Care Quality Commission should implement five autism-specific questions into their inspection framework, include autism in a Key Line of Enquiry and produce training brief guides on autism for inspectors.



of all respondents to our survey **think the CQC should check that health services are meeting the specific needs of autistic people**.

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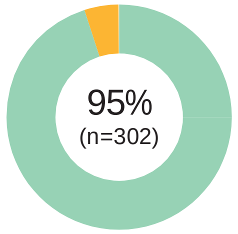
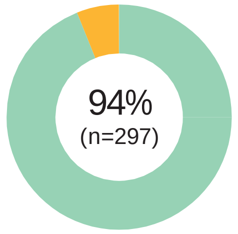
[13] Improvinghealthandlives.org.uk. (2016). Autism self-assessment 2014 :: Public Health England - Improving Health and Lives. [online] Available at: http://www.improvinghealthandlives.org.uk/publications/313914/Autism_self-assessment_2014 [Accessed 14 May 2016].

Recommendation Three – Data:

An anonymous national primary care register for autism should be created, based on a single diagnostic-code in GP records, to be introduced in consultation with a broad cross-section of the autistic and wider autism community. The Learning Disability Mortality Review should be extended to include a new Autism Mortality Review to learn about the premature mortality of autistic people in England.



of autistic respondents **want doctors to have a note on their computer screen to tell them that the patient is autistic**;



of autistic respondents would be **happy to be added to an anonymous database of autistic people to help improve services**.

Recommendation Four – Annual Health Checks:

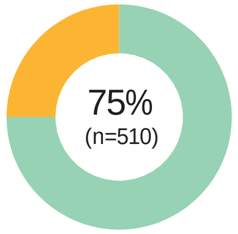
Once an anonymous national primary care register is in place, NHS England should use it to guide its work to reduce health inequalities for autistic people as outlined in the Government's Mandate. NHS England should consult with autistic people regarding the introduction of annual health checks to ensure that their unmet health needs are detected and treated and that they have a Health Action Plan in place. Such checks should be introduced if research evidence suggests they would be effective.

Recommendation Five – Leadership:

NHS England to appoint a National Clinical Director for autism and a senior lead member of staff for autism as well as ensuring additional capacity such that autism is considered across all NHS England work-streams, from Mandate to Business Plan, to make reduced health inequality a reality. Other health related bodies should follow suit.

Recommendation Six – Resources:

The Department of Health should launch a time-limited Autism and Health Innovation Fund for applications from Royal Colleges, professional bodies, third sector organisations and others to develop resources/aids/mentoring programmes to help autistic people access healthcare. Projects which are user-led should be the gold standard. Research funders should consider funding studies into preventing poor health in autistic people. Such research may prove a useful tool in indicating which resources/aids/mentoring programmes autistic people would benefit from.



of autistic and self-advocate and family-advocate respondents say they **would like help to understand what will happen when they go to the doctor or hospital**.

Contributors to Evidence Sessions

Jonathan Andrews FRSA, Trainee Solicitor, Autistic Self-Advocate and Equality Improvement Champion, **Mind** and Chair of Youth Council, **mbitious bout utism**

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*also a parent-advocate

PART ONE

BACKGROUND

1.1 Autism: The Basics

Autism is used in this report as a term encompassing all Autistic Spectrum Conditions (including Asperger's Syndrome and Pervasive Developmental Disorder Not Otherwise Specified/PDD-NOS). Autism is a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them. It's estimated that over 1% of the UK's population are autistic[14][15], with 700,000 autistic people living in the UK today and 2.8m lives touched by autism daily[16].

Due to the variable influence of autism on an individual's life, autism is conceived of as a spectrum condition.

Autism is not a mental health condition but according to one study, 70% of autistic children meet the criteria for a co-occurring mental health condition, and 40% meet the criteria for two[17]. Autism is not a learning disability but a significant proportion of autistic people have a learning disability (prevalence estimates vary but are often quoted to be approximately 50%)[18].

Awareness of autism is generally good and 99% of the general population have heard of autism[19] but understanding of the complexity of autism spectrum conditions and the ways in which these conditions affect communication, sensory experience and behaviour is not so good. Too many myths still exist which cloud true understanding and acceptance of autism, such as the belief autistic people lack all empathy or that everyone with autism is the same.

The 'hidden' nature of autism means that making reasonable adjustments for autistic people can be difficult. Often the adjustment will need to be made to communication techniques i.e. avoiding open-ended questions or providing easy-read information. Making reasonable adjustments for autistic people is perceived to be more complex than for someone with a visible disability for example.

There are a range of related co-occurring conditions associated with autism including ADHD and epilepsy.

People often misconceive autism as a childhood condition. Autism is a lifelong condition. People also stereotypically think of autism as a 'male' condition and the typical autistic person as a male child. It is true to say that there are more men diagnosed with autism than women. However, this may be due to a misunderstanding of the manifestation of autism in women as well as a possible male bias in diagnostic tools[20].

Despite the efforts of many to improve understanding and break down barriers, the autistic community all-too-often struggle with navigating a world attuned to the needs of neuro-typical people. Misunderstanding and resultant anxiety can characterise many autistic people's lives. Too many have to fight for the same opportunities and liberties that the neuro-typical population take for granted.

This report depicts the struggles that many have with accessing quality healthcare and living healthy and long lives.

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[14] Baird G, Simonoff E, Pickles A, et al. (2006) Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). The Lancet 368: 210–215.

[15] Brugha TS, McManus S, Bankart J, et al. (2011) Epidemiology of autism spectrum disorders in adults in the community in England. Archives of General Psychiatry 68: 459–465.

[16] Autism.org.uk. (2016). Autism facts and history - NAS. [online] Available at: http://www.autism.org.uk/about/what-is/myths-facts-stats.aspx [Accessed 14 May 2016].

[17] Simonoff E, e. (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. - PubMed - NCBI. [online] Ncbi.nlm.nih.gov. Available at: http://www.ncbi.nlm.nih.gov/pubmed/18645422 [Accessed 13 May 2016].

[18] Autism.org.uk. (2016). Autism facts and history - NAS. [online] Available at: http://www.autism.org.uk/about/what-is/myths-facts-stats.aspx [Accessed 14 May 2016].

[19] YouGov: What the world thinks. (2015). YouGov | More people in the UK are aware of autism. [online] Available at: https://yougov.co.uk/news/2015/04/13/more-people-uk-are-aware-autism/ [Accessed 14 May 2016].

[20] Lai, M., Lombardo, M., Auyeung, B., Chakrabarti, B. and Baron-Cohen, S. (2015). Sex/Gender Differences and Autism: Setting the Scene for Future Research. Journal of the American Academy of Child & Adolescent Psychiatry, 54(1), pp.11-24.

1.2 What we already know:
The Good and The Bad

Most autistic people should live long and healthy lives. However, a recent, large and high-quality Swedish study shows that autistic people that have a co-occurring learning disability see their life expectancy decreased by an average of 30 years and even those without a learning disability still have an average of 12 years deducted from their life expectancy[21]. We do not have reliable mortality figures for autistic people in the UK, but there is no evidence to suggest that our healthcare system is working better for autistic people than the Swedish system.

The Autism Act 2009 was a landmark in the battle to improve services for autistic people. The Act, associated 'Think Autism' Strategy and statutory guidance has done much to embed autism into local commissioning. Its focus has been predominantly on social care. However, the Government has included the need to reduce the health gap between autistic people and the general population in its mandate to the NHS.

The mandate cites prevention, early intervention and improved access to integrated services as necessary steps to begin to close the health gap and aims to achieve parity by 2020; an ambitious target. The Government has also supported the Autism Clinical Priority programme at the Royal College of General Practitioners (RCGP). Further, steps have already been taken by the Government to improve health outcomes for autistic people, particularly those with a learning disability. The Commission welcomes the world's first Learning Disability Mortality Review commissioned by NHS England. It is hoped that such a review will lead to improvements in services[22].

However, this mortality review does not address the possible loss of many years of life for those autistic people who do not have a learning disability as seen in Sweden. Furthermore, as this report will argue, there are autism-specific considerations to be made when addressing premature mortality. For example, the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) found that the leading causes of death was heart and circulatory disorders (22%)[23]. In contrast, the Swedish study has shown that the leading cause of premature death for people with both a learning disability and autism is epilepsy[24].

It cannot be assumed that the health gap for autistic people can be closed via initiatives primarily tailored for people with a learning disability.

The Government recognises that "When professionals do understand autism, the positive impact on the lives of adults with autism can be immense"[25]. The Autism Act enshrines the importance of autism-awareness training in health and social care settings and the statutory guidance makes it clear that staff across health and care should receive autism training. The Equality Act 2010 enshrines anticipatory reasonable adjustments in law.[26]

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[21] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P. and Bolte, S. (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), pp.232-238.

[22] Theyworkforyou.com. (2016). TheyWorkForYou. [online] Available at: http://www.theyworkforyou.com/wrans/?id=2016-03-22.32130.h&s=autism [Accessed 14 May 2016].

[23] bris.ac.uk. (2013). Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). [online] Available at: http://www.bris.ac.uk/media-library/sites/cipold/migrated/documents/finalreportexecsum.pdf [Accessed 19 May 2016].

[24] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P. and Bolte, S. (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), pp.232-238.

[25] Gov.uk. (2016) Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy, Department of Health (2015) Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf [Accessed 13 May 2016].

[26] Legislation.gov.uk. (2016). Equality Act 2010. [online] Available at: http://www.legislation.gov.uk/ukpga/2010/15/section/20 [Accessed 13 May 2016].

However, the requirement for NHS staff to be trained is hard to enforce and the 2014 self-assessment framework responses indicate that there is more to be done to monitor such training. Autism is not included in the different accountability mechanisms used for the NHS (e.g. the NHS Outcomes framework) and so NHS bodies are not incentivised in the same way as they are for learning disability and dementia to ensure that training is in place. Furthermore, there is no audit of reasonable adjustments to ensure that services routinely meet the needs of autistic people.

While there is mention of the need to close the health gap for autistic people in the Government's mandate to the NHS, there is no mention of autism in the NHS Business Plan nor in Public Health England's Remit Letter.

There is much to be commended in the Autism Act, Strategy and guidance. The Commission particularly welcomes the commitment to meet the asks of autistic people including:

"I want staff in health and social care services to understand that I have autism and how this affects me"
"I want services and commissioners to understand how my autism affects me differently through my life."[27]

The process for monitoring the implementation of the Autism Strategy is through the Autism Self-Assessment Framework managed by Public Health England on behalf of the Department of Health. This Self-Assessment framework is a useful tool. However, responsibility for the SAF falls on local authorities and the NHS is not properly held to account for the services it provides for autistic people.

While the Autism Act and strategy set out a clear direction of travel, the implementation is variable and not as fast as many respondents would like.

In securing access to quality healthcare, it is important that CCGs are involved in the planning and implementation of the autism strategy. The Government's statutory guidance recognises this.

However, some local areas are performing worse now than when self-assessed in 2013. In 2014/15, 39% of local authorities reported that CCGs, primary and secondary care practitioners are involved in planning and implementation. Action is needed to ensure that more CCGs are involved in multi-agency training plans in coming years.

There has been commendable progress made in improving services for autistic people. This should be used as a springboard to solve the access to healthcare issues autistic people are facing.

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[27] Gov.uk. (2016) Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy, Department of Health (2015) Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf [Accessed 13 May 2016].

[28] Improvinghealthandlives.org.uk. (2016). Autism self-assessment 2014 :: Public Health England - Improving Health and Lives. [online] Available at: http://www.improvinghealthandlives.org.uk/publications/313914/Autism_self-assessment_2014 [Accessed 14 May 2016].

1.3 The need for this inquiry

> “What autism really is, is an enormous population of men and women with tremendous potential who are being denied what everyone deserves: the chance to live a happy, healthy, safe, secure and productive life. Viewed in this light, autistic people are one of the largest disenfranchised minorities in the world.”
>
> **Steve Silberman at the UN April 1st 2016[29]**

Autistic people are at a significant but little understood disadvantage when trying to access healthcare. According to the Swedish study on premature mortality, autistic people, on average, have 12 years deducted from their life expectancy and on average, those that have a co-occurring learning disability die 30 years prematurely[30].

Why might autistic people die prematurely?

This is not yet well-understood. However, Autistica, the UK’s largest autism research charity, explains that autistic people “…Experience depression, anxiety and sensory overload… Can face significant issues in accessing healthcare…” and argue that “As we see in the general population, these factors may increase the likelihood of suicide and death from other causes. Further research is required to more accurately understand the multiple factors which can lead to early death in autism.”[31]

The Royal College of General Practitioners (RCGP) recognised the health inequalities experienced by autistic people and the statistical ‘invisibility’ of autism in the health system. Led by Dr Carole Buckley, the RCGP have made autism a clinical priority from 2014-2017. The RCGP is the professional membership body and guardian of standards for 50,000 family doctors. The clinical priority programmes have the power to influence change but the RCGP does not have statutory power over its members[32].

It is not just the RCGP who have recognised the health gap suffered by autistic people. The Commission is delighted that the Government has included the need to reduce the health gap in its mandate to the NHS. The Commission welcomes the Government’s ambitious target to close the health gap by 2020[33]. It is our hope that the recommendations made here will help to make this a reality.

> “We truly feel like the forgotten members of society where no one really gives a damn about us as long as we don’t make too much of a fuss or noise. Its driven me to depression thinking about how my child will be cared for by society when I am not longer around to fight his corner”
>
> **(Ravi Patel, Parent Advocate)**

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[29] Silberman, S. (2016). Autistic people are not failed versions of “normal.”. [online] ideas.ted.com. Available at: http://ideas.ted.com/autistic-people-are-not-failed-versions-of-normal-theyre-different-not-less/ [Accessed 15 May 2016].

[30] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P. and Bo lte, S. (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), pp.232-238.

[21] Cusack, J., Spiers, J., Shaw, S. and Sterry, R. (2016). Personal tragedies, public crisis. 1st ed. [ebook] Available at: https://www.autistica.org.uk/wp-content/uploads/2016/03/Personal-tragedies-public-crisis.pdf [Accessed 15 May 2016].

[32] http://www.rcgp.org.uk/membership.aspx

[33] Gov.uk. (2016). The Government’s Mandate to NHS England for 2016-17. [online] Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/494485/NHSE_mandate_16-17_22_Jan.pdf [Accessed 15 May 2016].

1.4 Methodology and Participation

The Commission Members were clear from the outset that all work done by the Commission should be informed by the authentic voices of autistic people and their families.

Autistic people have contributed to the inquiry at every stage; as Commission Members, through written evidence submissions, presenting oral evidence at Commission meetings, through our survey and in the writing of this report. The Commission is deeply grateful to over 900 autistic people, family-advocates and professionals who contributed to this inquiry.

The Commission gathered evidence through:

- Four oral evidence sessions held in the Houses of Parliament. The list of contributors to these sessions is listed on page 25.
- Written submissions of evidence from autistic people and parent-advocates. The opportunity to contribute written evidence was advertised via social media and contributors used a framework of questions to structure their submission. An easy-read framework of questions was also available.
- Some contributors chose to input via a telephone interview. The same framework of questions was used.
- 863 autistic people, family-advocates and professionals contributed via our survey (697 complete responses – 81%). The survey pathways varied according to the respondent’s connection to autism. Some respondents had multiple connections to autism. For example, they might have been a parent, an autistic person and an academic. There were 1133 total connections to autism. In some cases, questions were only asked if the respondent was autistic or a parent-advocate. In other cases the question was asked regardless of the respondent’s connection to autism. Therefore, the percentages in this report are accompanied by a note as to which respondents were asked the relevant question.

Our ‘Access to Healthcare’ survey was constructed and managed by Craig Kennady, an autistic self-advocate, parent-advocate and campaigner. Craig used ‘Survey Monkey’ to build the survey and wrote the questions with some input from other members.

The survey sought both open-ended and quantitative responses. Permission to share responses in this report was granted by respondents however all names have been changed to ensure confidentiality. The survey was open from 22nd April 2016 to 9th May 2016.

Survey respondents were recruited using convenience sampling methods and internet snowballing methods through social media. Commission Members shared the survey in their networks. This means that the respondents are a self-selecting group and there are limitations associated with the survey results.

These results are not representative of the autistic population at large but give an indication of the feelings and experiences of this population.

PART TWO

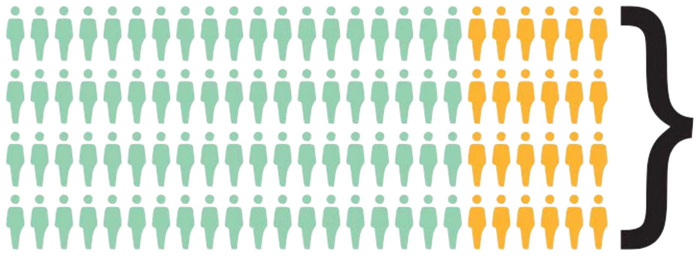
OUR FINDINGs

2.1 Obstacle One: Lack of Understanding

One of the most commonly reported obstacles faced by autistic survey respondents, in accessing the healthcare they need, is the perceived lack of autism understanding among health professionals. The Commission does not seek to criticise hard-working, well-intentioned and compassionate professionals of whom there are many but not enough doing good work in this field. However, it does seek to expose the limited quality, advocate-led, autism training for health professionals and the lack of understanding among health professionals perceived by our consultation respondents.

Few health professionals have any quality autism training as a part of their initial qualification or their Continuous Professional Development (CPD) training. In a recent survey, 40% (n=304) of GP respondents reported receiving **no autism training** in either their degree qualification or during their training or practice as a GP[34]. The same survey found that GPs reported low confidence in consulting with and managing autistic patients. 65% (n=440) of our survey respondents think that healthcare professionals 'rarely' or 'never' understand the physical and mental health needs of autistic people. Health services are expected to make reasonable adjustments under the Equality Act 2010[35].

According to the National Audit Office, 80% of GPs feel that they need additional guidance and training to identify and manage patients with ASD more effectively[36]. This may be related to lack of confidence due to unclear referral pathways and lack of support services[37]. If GPs do not have the resources to appropriately manage their autistic patients, patients may perceive their GP to lack understanding. More research would be needed to make a conclusion on this.



74% (n=497)

of all survey respondents **felt that autistic people receive a 'worse' or 'much worse' heath service than their non-autistic counterparts**.

75% (n=440)

of all survey respondents **felt that healthcare professionals 'rarely' or 'never' understand autism and how it affects someone's physical and mental health**.

We have heard a number of examples of health professionals suggesting that medical treatment, ranging from dental braces to a kidney transplant, should be withheld due to the patient's autism. We have also received many stories of autistic people subjected to pain, illness and prolonged suffering because their health care professionals did not understand, or could not manage, their needs and behaviours.

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[34] Ibid.

[35] Legislation.gov.uk. (2010). Equality Act 2010. [online] Available at: http://www.legislation.gov.uk/ukpga/2010/15/contents [Accessed 17 May 2016].

[36] Survey of General Practitioners in England on the subject of autism, Report prepared for The National Audit Office 2008 Available at: https://www.nao.org.uk/wp-content/uploads/2009/06/0809556_gp.pdf [Accessed 13 May 2016]

[37] Unigwe, S., Buckley, C., Crane, L., Kenny, L., Remington, A., & Pellicano, E. GPs' perceived self-efficacy in the recognition and management of their autistic patients. Manuscript in preparation.

“I had gallstones which were super painful for 10 months. I told dr it was 10/10 pain but because I didn’t scream they didn’t believe me. They didn’t know autistic people may not scream when in pain.

I had a scan. Dr stopped scan and sent me for operation as he said pain would be equivalent to child birth. I did tell them it hurt. They didn’t listen”

Jonny Kingsley,
Autistic Self-Advocate

“We had to go to hospital for a minor op. It was probably the worse experience of my life. They had no understanding at all. My poor son was so deeply traumatised. He was terrified. He and myself came home bleeding. He ripped the needle out of his hand. Hurt himself. When i asked had they ever experienced a child with Autism they said yes but not that bad. We had more help from the other parents because they could see how bad it was.”

Janice Ip,
Parent-Advocate

“… last time I had to attend hospital for a emergency op they wouldn’t take my needs into consideration and I refused to stay and went untreated”

Brenda Crosby,
Autistic Self-Advocate

“Personally, I don’t like talking. I don’t know how to estimate my pain. I don’t know what questions I will be asked, and so when the questions come as a surprise I find it hard to figure out what the answer is. I have to revise what my symptoms and problems are beforehand, but I still find it really hard to recall them when surprised with questions. I saw a psychiatrist once who refused to read the notes I had written out beforehand on how I would like him to approach our session. I couldn’t verbalise them either.”

K,
Autistic Self-Advocate

“…it would have been so, so good if the GPs I have seen over the years had enough training to spot the signs proactively – then I could have been diagnosed years ago, and lived a richer life”

Nathan Ramsbotham,
Autistic Self-Advocate

“GPs have little understanding of autism and how it may affect those with an ASD… Sensory issues and time to process information are often not acknowledged…
The unusual reaction to pain is also not recognised by many GPs until it is pointed out to them”

Sandra Kirsty,
Parent-Advocate

2.2 Obstacle Two: Autism and Co-occurring Conditions

Historically, it has been assumed that the physical health needs of autistic people are the same as the neuro-typical population. It is fast becoming apparent that this is not true.

The physical health needs of the autistic population are complex and need specialist consideration. However, very few healthcare interventions have ever been scientifically validated to determine whether they are autism-appropriate. There is a need for research to address this gap.

Autism rarely presents with core symptoms alone. There are a huge range of co-occurring conditions which can accompany autism. The associated condition (or co-occurring condition) can significantly change the physical health needs of an autistic person. But health practitioners may not always understand these conditions:

88%

(n=597)

of all survey respondents told us that they **feel health professionals do not understand the conditions which co-occur alongside autism**.

Research is needed to establish the confidence of healthcare professionals in managing autistic patients with co-occurring conditions.

Healthcare professionals may not know and understand the core symptoms of autism and the interplay with co-occurring conditions. Those professionals who have some awareness of autism may be more likely to look out for co-occurring conditions.

There have been limited studies into the interplay between physical co-occurring conditions such as epilepsy, for example, and autism. This is a concern and should be a priority for research. Epilepsy has a prevalence of 0.97% in the general population[38] but has an incidence of more than 20% in the autistic population[39]. It is becoming increasingly clear that the combination of epilepsy and autism needs to be understood. A large, quality Swedish study shows that autistic people who also have a learning disability die an average of 30 years prematurely[40]. The leading cause of death is epilepsy. Yet we do not have a good understanding of the relationship between these two conditions nor do we have specialists or specialised treatment to tackle this.

But it is not just epilepsy that autistic people are more susceptible to. The same Swedish study found that autistic people die prematurely in almost all cause-of death categories. Cancer, cardiovascular disease, congenital malformations and almost all other diseases are causes of premature death in this autistic group. But reducing the obstacles to accessing healthcare can improve the detection and treatment of these diseases and improve life expectancy.

Other studies have found that autistic patients appear to be more susceptible to stroke, Parkinson's disease, gastrointestinal and sleep disorders, diabetes and immune conditions[41].

Without a holistic understanding of the autistic person's physical health needs and without a person-centred approach to this, the health needs of autistic people may go unmet.

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[38] epilepsyscotland.org.uk. (2011). Epilepsy prevalence, incidence and other statistics. [online] Available at: http://www.epilepsyscotland.org.uk/pdf/Joint_Epilepsy_Council_Prevalence_and_Incidence_September_11_(3).pdf [Accessed 15 May 2016].

[39] Bolton, P., Carcani-Rathwell, I., Hutton, J., Goode, S., Howlin, P. and Rutter, M. (2011). Epilepsy in autism: features and correlates. The British Journal of Psychiatry, 198(4), pp.289-294.

[40] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P. and Bo lte, S. (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), pp.232-238.

[41] Croen, L., Zerbo, O., Qian, Y., Massolo, M., Rich, S., Sidney, S. and Kripke, C. (2015). The health status of adults on the autism spectrum. Autism, 19(7), pp.814-823.

2.3 Obstacle Three: Co-occurring Mental Health Issues

Autism is not a mental health condition. However, in addition to experiencing physical co-occurring conditions, up to 70% of autistic children have at least one co-occurring mental health condition[42]. Further studies indicate significantly increased suicidal thoughts among autistic people[43]. Unfortunately, all-too-often when autistic people do develop mental health problems, the NHS is not always able to help them effectively.

"Mental health services openly, and unashamedly, tell me that they know very little about autism and certainly the services they offer are tarnished by this inability to recognise autism - e.g. emphasis has been on encouraging general socialising without knowing ASD limitations and/or have use of metaphors in their programmes."
Sam Hall, Autistic Self-Advocate

The Mental Health Taskforce was a welcome step towards improving mental health services for all users. The Taskforce's report 'The Five Year Forward View for Mental Health' did note that "People of all ages...who have multiple needs such as a learning disability or autism are also at higher risk."[44]

> "Autism is of growing interest to mental health services and is a condition that deserves special attention. If mental health staff are not trained to deal appropriately with autistic people, they will not meet the needs of this population group. We cannot tolerate autistic people having their mental health needs unmet; particularly as the suicide risk can be higher among autistic people."
> **Steven Michael OBE, Ex-Chair of the NHS Confederation Mental Health Network**

Our evidence suggests that mental health staff are not well-trained in autism. The Commission heard of multiple cases of misdiagnosis and missed diagnosis of mental health issues among autistic people. Some people do not receive a secondary diagnosis of a mental health issue because their symptoms are dismissed as being 'part of autism'. Others are diagnosed with a mental health condition and are not referred on for an autism diagnosis.

Mind have recently been involved in this area, having produced a toolkit in 2015 entitled 'Supporting people living with autism spectrum disorder and mental health problems[45]. Mind found that mental health services tended to either ignore peoples' autism or overlook their mental health issues instead, and sometimes try to 'treat' autism itself as though it were a mental health condition.

One person with Asperger's and bipolar highlighted in the booklet, Lucy, said: "I am just me – a whole person with my own unique personality, rather than a set of symptoms which can be easily recognised to one of my 'conditions'".

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[42] Simonoff E, e. (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. - PubMed - NCBI. [online] Ncbi.nlm.nih.gov. Available at: http://www.ncbi.nlm.nih.gov/pubmed/18645422 [Accessed 13 May 2016].
*Also a Self-Advocate and a Parent-Advocate

[43] Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M. and Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. The Lancet Psychiatry, 1(2), pp.142-147.

[44] england.nhs.uk. (2016). The Five Year Forward View for Mental Health. [online] Available at: https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf [Accessed 15 May 2016].

[45] mind.org.uk. (2015). Supporting people living with autism spectrum disorder and mental health problems. [online] Available at: https://www.mind.org.uk/media/3120340/autism-guide-web-version.pdf [Accessed 15 May 2016].

The recent Swedish finding that those autistic people without a learning disability die an average of 12 years prematurely is unacceptable but the finding that suicide is a leading cause-of-death is saddening.

As a result of the work of the Mental Health Taskforce, a new ‘autism pathway’ will be developed within the NHS. It is vital that the specific mental health needs of autistic people are looked at as the pathway is developed and that those on the spectrum who have experience of mental health services are involved in the pathway development.

In addition to the Swedish finding, a study conducted in the UK also found significant suicidal thoughts among the autistic population[46]. We need a better understanding of the suicide risks in this population. This could be achieved through a new Autism Mortality Review.

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[46] Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M. and Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. The Lancet Psychiatry, 1(2), pp.142-147.

2.4 Obstacle Four: Diagnostic Overshadowing

Autistic people repeatedly told us that they have their health concerns dismissed as being ‘just a part of their autism’. It is possible that a lack of understanding among health professionals leads to co-occurring conditions being mistakenly seen to be part of the autistic spectrum condition. This is certainly the perception of those who contributed to our inquiry.

The autism label can overshadow other possible physical or mental health diagnoses and sometimes other diagnoses may overshadow a possible autism diagnosis. Some autistic people and parent-advocates feel that health professionals have lower expectations for the health of an autistic person. This may be due to health professionals not receiving good-quality training on what is, and what is not, a core aspect of autism.

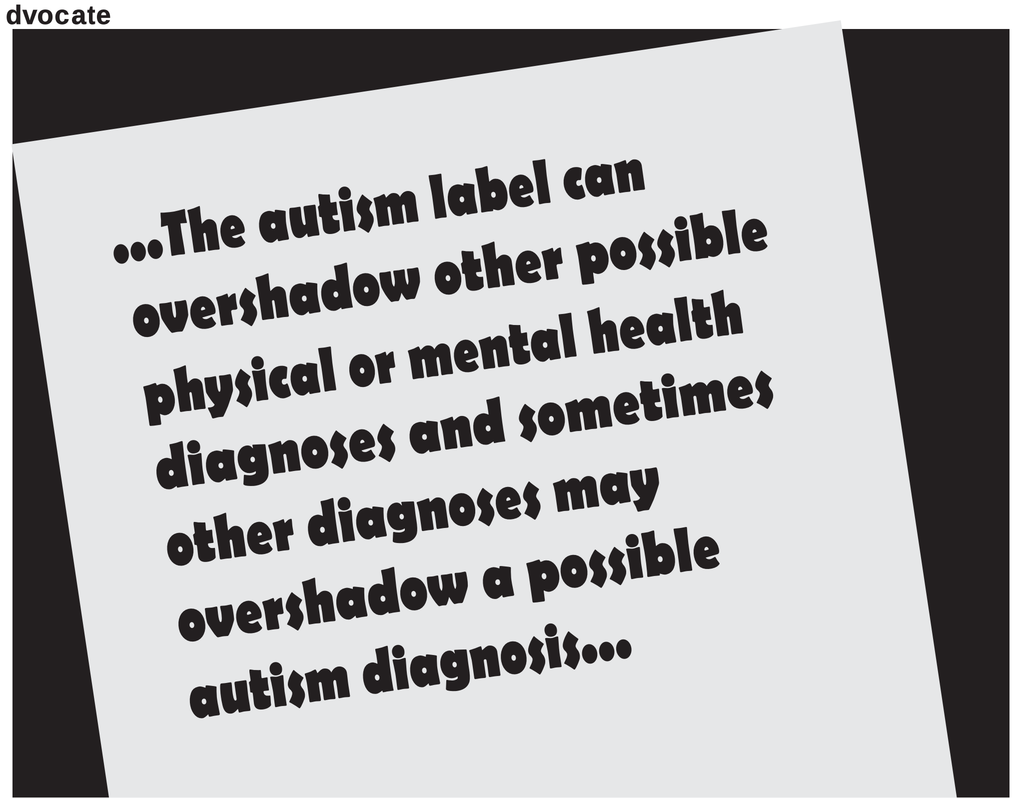
One mother told us that her autistic son’s epilepsy was uncontrolled. He was having an average of three seizures per year and each of these would have significant consequences to his health; he was a 6-foot-tall, 17-year-old who would crash to the floor with each epileptic episode. The doctor felt that this level of control was satisfactory. But his mother felt that if he had been a non-autistic 17-year-old, three seizures a year would not have been considered acceptable; he would be wanting to drive and be independent and every effort would be made to make this possible and control his epilepsy accordingly.

Autistic people often feel that they have to fight harder than non-autistic people to have due attention given to their physical and mental health needs.

Autistic people should not have to accept poor physical or mental health. Non-autistic people do not expect to live with substandard physical or mental health and nor should autistic people. But in order for autistic people to have their health concerns taken seriously, health professionals need to understand what exactly is and is not a core symptom of autism and what can be treated. This requires them to receive quality training developed and delivered by autistic people.

“It seems difficult for medical staff to get beyond people’s autism and accept they may also have a co-occurring medical issue”

Sandra Kirsty, Parent- dvocate



...The autism label can overshadow other possible physical or mental health diagnoses and sometimes other diagnoses may overshadow a possible autism diagnosis...

2.5 Obstacle Five: Sensory Processing and Communication

Autistic people can experience severe sensory processing abnormalities[47]. Respondents told us that when someone experiences too much sensory input, they can meltdown or become agitated, anxious and upset. Many autistic people and parent-advocates wrote to the Commission to tell us that one of the biggest barriers to accessing healthcare services is the sensory experience of the environments.

Respondents told the Commission that waiting in loud, busy and brightly-lit waiting rooms that smell of disinfectant and feature a bombardment of posters on the walls, can induce sensory overload in autistic people. Once the overload takes place, it is difficult for the individual to re-regulate their senses. It is extremely difficult for the autistic person to communicate their health needs to a professional when experiencing sensory overload.

Not only does sensory overload cause upset, it can cause physical symptoms. “sensory overload caused by bright lights, fluorescent lights, colours, and patterns makes the body react as if being attacked or bombarded, resulting in such physical symptoms as headaches, anxiety, panic attacks or aggression”[48]

There is a relevant interplay of an intolerance of uncertainty, sensory sensitivities and anxiety in autistic people which may be exacerbated in healthcare environments[49]. Healthcare environments are, for most people, attended irregularly and carry a degree of uncertainty with them.

Such uncertainty can be intolerable for autistic individuals, the sensory experience of a healthcare environment unbearable and the anxiety induced insufferable.

> “It’s the not knowing what will happen, how long it will all take, will I have to take my clothes off, how many people will I have to interact with, will I have to stay overnight. All these unknowns mean that you end up torturing yourself about what might happen from the moment you make the appointment until the moment you are released.”
>
> **Adam Fredrick, Autistic Self-Advocate**

There is an inevitable knock-on effect of such experiences on the healthcare provision possible. One mother told the Commission “... my autistic son had a seizure and was taken to the children A&E. Despite the Dr saying they had experience of autistic people it became apparent quite quickly they lacked the experience to converse in a way that my son understood. He was extremely stressed as he came around from his seizure in a different place, a noisy environment, one which caused a sensory overload so he sat on the bed underneath his hoodie and rocking for comfort. The Dr asked if he could hear voices - his reply was yes. They then started talking about a psychiatrist assessment. When I reworded the question to what voice can you hear he responded with yours and the Doctors. This was a completely different interpretation by my son and one that I was able to help him with.”

…>

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[47] Crane, L., Goddard, L. and Pring, L. (2009). Sensory processing in adults with autism spectrum disorders. Autism, 13(3), pp.215-228.

[48] Williams, D. (1994). Somebody somewhere. New York: Doubleday. P.43

[49] Neil, L., Olsson, N and Pellicano, E. (2016) The Relationship Between Intolerance of Uncertainty, Sensory Sensitivities, and Anxiety in Autistic and Typically Developing Children. J Autism Dev Disord.

This is an episode of sensory overload and distress that resulted in a problematic breakdown in communication between a healthcare professional and an autistic patient.

Some autistic people reported to us that communicating needs to a health professional can also be impaired by ‘Autism Fatigue’[50]. There is a lot of anecdotal evidence to suggest that autistic people have to expel huge amounts of energy to cope in a world attuned to the needs of neuro-typical people. Countering sensory overload and navigating social situations can cause exhaustion to become entrenched. Jonathan Andrews presented to the Commission on this concept and explained that some people can appear externally to be coping but they burn a lot of energy in keeping up appearances. When experiencing such fatigue, it can become challenging to communicate health needs to a professional.

It is, therefore, unsurprising that so many autistic people told us that they feel that consultations with healthcare professionals are all-too-often unsatisfactory. There is much more to be done to ensure that autistic people can confidently and easily access healthcare environments and benefit from quality consultations that are commonplace for non-autistic patients.

> **...Many autistic people and parent-advocates wrote to the Commission to tell us that one of the biggest barriers to accessing healthcare services is the sensory experience of the environments...**

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[50] Andrews, J. (2016) “Autism: Sorting Fact from Fiction”. https://www.thersa.org/discover/publications-and-articles/rsa-comment/2016/01/autism-sorting-fact-from-fiction. Royal Society of Arts. Includes links to several blogs which discuss personal experiences of autistic fatigue.

2.6 Obstacle Six: Leadership of Autism in the Health System

There seems to be widespread agreement that there are problems in getting healthcare right for autistic people. But who's problems are they?

Barriers to accessing healthcare can be put up by the very structure of the health system itself. There is no single group of health professionals who take responsibility for autism and own the issues associated. Thus, there are few who champion autism and fight for the best for autistic people within the health sector. Kate Bamforth, a Learning Disability Liaison Nurse, explained that her liaison team take ownership of the healthcare for people with a learning disability but are not commissioned to do the same for autistic people who have an IQ >70. However, it should be emphasised that many individual healthcare professionals make every effort to provide excellence to their autistic patients.

There is an autism-lead in the Department of Health but there is no counterpart autism-lead in NHS England. **NHS England does not have a National Clinical Director for autism. Identifying a lead-person can be a way of galvanising progress.** This has been demonstrated through the appointment of Dr Carole Buckley as the Clinical Champion for Autism at the RCGP.

case study

A little leadership goes a long way!

The Royal College of GPs made autism a clinical priority from 2014-2017. They received £32,000 of Department of Health funding. This grant from the Department of Health has enabled the College to campaign for improved healthcare for autistic people:

Cascade training out to 8000 GP practices

Four faculty conferences delivering the connect autism training

Training components in training for non-clinical staff including receptionists

Produced GP friendly materials with top-tip consultation skills

Resources for patients and carers on how to get the most out of your consultation

Autism Charter to be promoted in GP practices

A closed Facebook page – supporting clinicians who are autistic, or parents or siblings of autistic family members

The entire April 2016 edition of Clinical News dedicated to autism – read by 50,000 GP College members with top tips

Production of a new e-learning module in May

Curriculum for training new GPs under review

Autism in the CPD for GPs

Three articles in Innovate – the GP's in training magazine

Produced a GP Toolkit which is a 'one stop shop' for autism resources

2.7 Obstacle Seven: Isolation, Avoidance, Inertia and Neglect

Despite having significant risks to their health, autistic people told us that they avoid healthcare environments and their health can suffer as a result.

Autistic Commission Member, Helen Ellis, told the Commission that some autistic people do not recognise their symptoms as unusual or make the connection between poor health and the need to proactively seek help from a professional. However, many of those that do recognise their symptoms and understand the need for professional help told us that they avoid attending healthcare environments. More research is needed to understand avoidance behaviours in the autistic population and the possible impact on access to healthcare and health outcomes.

Many told us of the crippling fear and anxiety that healthcare environments and professionals induce. The anxiety can result in a total inability to communicate their needs with the professional and can result in unsatisfactory and upsetting consultations.

Dr Yo Dunn told the Commission that "A large proportion of autistic people 'struggle to do stuff' even when highly motivated to achieve the task and no matter how much information is provided. Many need prompting and other support in order to achieve everyday tasks including taking medication, making and attending appointments and other health-related tasks."

Numerous advocates reiterated this point; that autistic people can struggle to complete tasks and can forget to do essential health-related tasks.

In addition, parent-advocates of autistic people told us many times of healthcare needs going unmet due to behaviour that challenges and poor understanding among healthcare professionals. One parent-advocate told us:

> "There is absolutely no chance of me getting him to take medicine. I don't know what we would do if he was ever very ill. I daren't even think about it"
>
> **Malachi Akram, Parent-Advocate**

Heather Tanner (a Parent-Advocate) told the Commission that her son John is eligible for an NHS Annual Check because he has a learning disability (he is also autistic). Sadly, John's health-check detected major kidney failure. Heather recounted her concerns when the hospital questioned whether John should be put onto dialysis treatment due to his mental capacity to cope with the procedures. Similarly, when discussing a kidney transplant, the hospital suggested that John might not be able to cope with surgery.

John needed blood tests three-times a week after his transplant. To do this, John was repeatedly restrained by four of five healthcare staff in corridors (he was too frightened to enter the room). Heather explained that she felt that resorting to restraint was unnecessary and asked for a community nurse to draw blood in John's home. This was refused. Heather now takes John's blood herself.

John's story is one of many stories which show a lack of training, skill or confidence in caring for autistic people. 74% (n=497) of respondents felt that autistic people receive worse or much worse healthcare than non-autistic people.

If John's mother had not stepped in to meet his needs, they may have gone unmet.

Making healthcare accessible to autistic people inextricably involves social care. Without an advocate, many contributors told us that they would end up not accessing healthcare services at all.

> "Dentists – my tooth fell apart. Dentist was going to refer me. But they didn't. Will go dentist again when friends less busy. My teeth hurt every day"
>
> **Jonny Kingsley,**
> **Autistic Self-Advocate**

> "I can't actually get to the doctors currently as my support has gone – so am getting more ill physically- sores due to no support, not following medications properly and little things like sinus infections (since christmas) and breathlessness (for months now) are just collecting and not getting sorted"
>
> **Toby Adeyemo,**
> **Autistic Self-Advocate**

> "I found that Andrew could easily have been completely excluded from the Doctors because he forgot to attend"
>
> **Angela James,**
> **Parent-Advocate**

Avoidance behaviours in a population who have increased health risks is an undesirable combination. More research is needed to establish such behaviours in the autistic population.

If health services are failing to meet the needs of others like John, it is possible that some autistic people may 'give up' on services which could lead to neglect of health needs. This could be particularly pronounced among those that do not have a strong and supportive advocate like Heather to insist on them having their needs met. As in the general population, social isolation will play into this lack of a support network and the possible resultant neglect. Autistic people are frequently socially isolated, yet often need someone else to assist them with their health needs.

"I avoid both [the GP and the hospital] unless I am in agony. Going out to either requires hours or usually days of psyching myself up/mentally preparing. I have 3 as yet undiagnosed health problems/worries that I can't sum up the courage to make the trip to the doctor's for. I'd rather suffer at home than talk to strangers (don't even like talking about it with family). If you want to see your own doctor you have to wait weeks for an appointment if you need to see someone sooner you have to take pot luck with a locum or another doctor you've never seen before."
Adam Fredrick-Hamilton, Autistic Self-Advocate

2.8 Training for Excellence

Health Education England was established as a Special Health Authority in 2012 and became a Non-Departmental Public Body on 1 April 2015, under the provisions of the Care Act 2014. Its role is to "…support the delivery of excellent healthcare and health improvement to the patients and public of England by ensuring that the workforce of today and tomorrow has the right numbers, skills, values and behaviours, at the right time and in the right place."[51]

Responsible for training staff for the NHS and developing those already working within healthcare, Health Education England works to ensure that undergraduate, postgraduate and Continuous Professional Development courses train and equip staff appropriately.

Health Education England has developed online autism awareness training resources available through 'eLearning for Health' and 'MindEd' on the Health Education England website and lists quality assured training available from other organisations[52]. These resources are free to use and available to everyone working in health and social care and beyond. Health Education England monitors who is accessing them. Health and social care service provider organisations are responsible for ensuring that their workforce is benefitting from these resources and developing the right skills, values and behaviours to deliver care excellence. All training resources should include autistic people in their production and delivery.

There is no national mechanism to ensure that the health workforce is benefitting from any available resources and developing the right skills, values and behaviours to deliver excellent healthcare and health improvement.

The statutory guidance that accompanies the Autism Act stipulates states that autism-awareness has to be included in all equality and diversity training for health and social care staff and that CCGs have to ensure that both general awareness and specialist autism training is provided on an ongoing basis.

Only 29% of local areas have made autism-training available to all health and social care staff[53].

The strongest piece of evidence to come out of our inquiry is the vital need for ensuring that all healthcare professionals are accessing quality training. Autistic people are the experts in their condition and training is the message repeated time and time again. If NHS England is going to close the health gap for autistic people, all staff must be well-trained. Design and delivery of training should include autistic people.

Dr Yo Dunn, Independent Consultant and Trainer, told the Commission that financial incentives and/or strong specific statutory duties would be required to actually achieve significant change in current practices in positive rather than negative directions.

@W_Autism_Comm major improvement would be if GP's and mental health workers had quality autism awareness training. Could be transformative

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[51] Health Education England. (2015). Health Education England. [online] Available at: https://hee.nhs.uk/ [Accessed 17 May 2016].
[52] Health Education England. (2015). Autism. [online] Available at: https://hee.nhs.uk/our-work/hospitals-primary-community-care/mental-health-learning-disability/learning-disability/autism [Accessed 17 May 2016].
[53] Improvinghealthandlives.org.uk. (2016). Autism self-assessment 2014 :: Public Health England - Improving Health and Lives. [online] Available at: http://www.improvinghealthandlives.org.uk/publications/313914/Autism_self-assessment_2014 [Accessed 14 May 2016].

2.9 Commissioning for Excellence

"Commissioning is seen as a key means of helping achieve a wide range of policy objectives in the NHS, including improving the safety and quality of services; creating better value for money and wider patient choice; and reducing inequalities in health."[54]

Clinical Commissioning Groups have statutory responsibility to commission most NHS services that the CCG deem to be necessary to meet reasonable local needs.[55] Clinical Commissioning Groups may struggle to meet the needs of autistic people if they do not have an understanding of autism, lack data on their local autistic population and do not have strong partnerships with local Autism Partnership Boards.

The inclusion of the autism health gap in the NHS mandate is a significant step in a positive direction. However, the NHS Business Plan for 2016/17 does not mention reducing inequalities in health for autistic people.[56] Statutory guidance does note that "Commissioning decisions need to be based on knowledge and awareness of autism, the needs of the local population, and informed by people with autism and their families"[57] This commitment by the Government is welcome.

In his evidence to the Commission, Dr Phil Moore (Deputy Chair of Kingston CCG and Board Member of the NHS Clinical Commissioners) mentioned the need for training for commissioners to ensure that they commission local services with autism in mind. Health Education England should seek to ensure that Commissioners receive quality, self-advocate led, autism-training.

The local needs can also be communicated to CCGs through local Healthwatch branches. Healthwatch Cheshire East shared an example of their work with the Commission which led to improved diagnostic services for autistic people. Healthwatch England should encourage all local branches to consult their local populations on autism related issues and take these to CCGs to see changes made.

In order for services to meet the health needs of autistic people, commissioners need to understand autism and be made aware of the local needs of autistic people. This requires commissioners to receive quality training and have access to data regarding the health needs of local autistic people.

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[54] Researchbriefings.parliament.uk. (2016). Research Briefings - The structure of the NHS in England. [online] Available at: http://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7206#fullreport [Accessed 15 May 2016].

[55] ibid

[56] england.nhs.uk. (2016). Our 2016/17 Business Plan. [online] Available at: https://www.england.nhs.uk/wp-content/uploads/2016/03/bus-plan-16.pdf [Accessed 15 May 2016].

[57] gov.uk. (2015). Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy. [online] Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf [Accessed 15 May 2016].

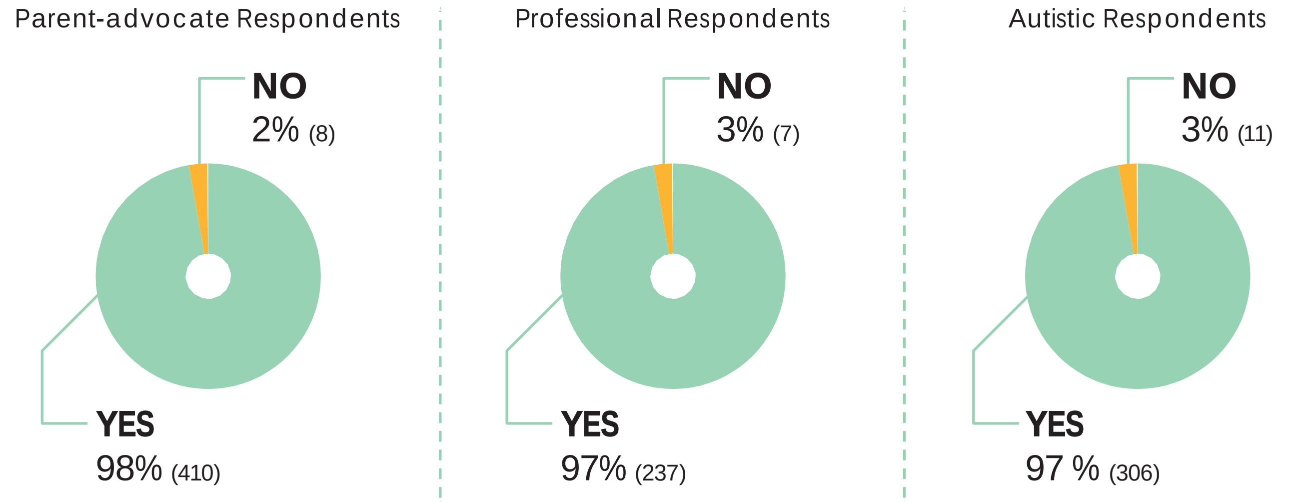
2.10 Inspecting for Excellence

The Care Quality Commission is the independent regulator of health and adult social care in England. Inspections of health and social care providers are structured around five key questions:

- Are they safe?
- Are they effective?
- Are they caring?
- Are they responsive to people's needs?
- Are they well-led?

There is currently no autism-specific question included in any CQC healthcare inspection framework. There are two references to autism within a Learning Disability question but only in reference to LD wards in a mental health service or community mental health services.

Do you think that the Care Quality Commission should check that health services are meeting the specific needs of autistic patients?



> "We are satisfied that we look actively for services meeting the needs of people with autism in LD wards. We are less likely within mental health and even more less likely in acute hospital settings and in primary care."
>
> **Dr John Devapriam, CQC**

···>

Inspections carried out by the CQC are structured around Key Lines of Enquiry (KLOE). The framework accompanying the KLOE R2 “Do services take account of the needs of different people, including those in vulnerable circumstances?” mentions dementia and

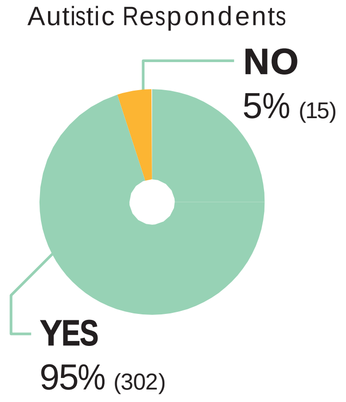
LD but does not mention autism.

The five questions used to inspect healthcare provision for patients with a learning disability could easily be extended for autism. There is a video clip and brief guide available to train inspectors on LD issues but there is nothing for autism. Autistic people are not routinely used in inspections as Experts by Experience.

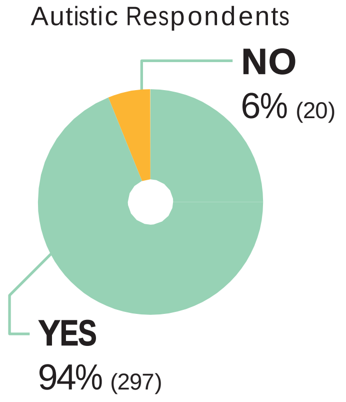
The CQC do not ask any autism specific questions in their healthcare inspections. 97% (n=748) of survey respondents felt that the CQC should ensure that health services are meeting the specific needs of autistic people.

2.11 Collecting Data for Excellence: The Statistical ‘Invisibility’ of Autism in the Health System

Would you like your doctor to have a note on their computer to tell them that you are autistic?



Would you be happy for your GP/ doctor to add you to an anonymous database of autistic people to help improve services?



There have been some positive developments in terms of data collection including the new premature mortality review on LD which will review every death of people with a learning disability wherever they are in the health service. Similarly, autism is now part of the Mental Health Minimum Data Set (MHMDS). Both the LD mortality review and the MHMDS will begin to provide the necessary data to make positive changes for autistic people.

However, there are concerns that data on autism is all-too-often fractured according to additional conditions such as LD or mental health and therefore the specific data on autism is patchy. The new premature mortality review for LD does not account for those autistic people who do not have a learning disability but may still die prematurely. The Commission met with Public Health England, NHS England, Dr Yo Dunn and Professor Gillberg to discuss the role that data collection plays in improving healthcare.

Commission Members were displeased to see the incompleteness and lack of data available to Public Health England. Hospital admissions data is inconsistently collected such that it appears to show that most autistic people never go into hospital. Furthermore, we know that the Swedish study shows that suicide rates are nine-times higher for autistic people[58]. Such deaths are investigated by a coroner in this country but autism is very rarely mentioned on death certificates. Death certificate data shows no increased prevalence of suicide in autistic people; it is incomplete, inconsistent and unusable.

How will commissioners and healthcare professionals meet the needs of autistic people if their needs are not monitored?

NHS England told the Commission that currently there is inconsistent identification of autistic patients; something which frustrates many of those who sent written submissions to the Commission. Our survey respondents have made it clear that they would like their GP to have a flag on a computer screen to tell them that they are autistic. 95% (n=302) of autistic people would like their doctor to have a note on their computer screen to tell them that the patient is autistic.

It is clear that a range of professionals believe that we need to start recording autistic people’s use of health services and that the first step in doing so would be to have a consistent diagnostic-code for autism and an anonymous National Primary Care Register for autism.

...>

[58] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P. and Bolte, S. (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), pp.232-238.

> "We have inconsistent identification and flagging systems…For healthcare professionals it is really helpful to have a flag either on a register, or on a system or on a record. Such that we know we have got to do something different…to make a reasonable adjustment...to change the way we provide the service… From a purely NHS point of view, it [a flag] is really helpful such that we can start to know how well, or otherwise, we are doing"
>
> **Hazel Watson, NHS England**

> "Having a diagnostic code recorded in primary care data systems for autism... is the sine qua non for improvements in outcomes."
>
> **Professor Christopher Gillberg, University of Gothenburg, Sweden.**

> "Currently there isn't a register for people with autism [in the QOF]…if that changes, it would substantially enhance the chances in the beginning to get some data. We have recently had successes in getting a lot of data about the primary healthcare of people with learning disabilities…by getting anonymised extracts …which has been very effective... If we had QOF registers for autism we would be able to do the same for people with autism."
>
> **Professor Gyles Glover, Public Health England**

However, it is extremely important that data collection always considers the concerns of the autistic population.

Dr Yo Dunn explained to the Commission "Concerns have been expressed by a significant number of autistic people about 'registers' or any information collection which potentially allows the identification of individual patients. **Statistical information which cannot be used to identify individuals raises far fewer ethical concerns and would clearly be of benefit in tracking progress on healthcare outcomes.** I think many people would like to see improvement in the collection of data on the whole autistic population (without the fracturing of the autistic population and/or merging with other groups e.g. learning disabilities/ mental health etc.)"

The concern about the use of a register collected which could identify individual autistic people has been raised by others including Helen Ellis, Commission Member:

"I understand from a research point of view why data is very important. The minute you start talking about a register my mind is screaming - You haven't convinced me why I should be on it! You haven't told me what you are going to want from me, what you're going to do with it, where it is going to be stored. I don't want to go on a list that in 20 years-time, a social worker is going to pull out and go 'yeah [you're autistic]...you can't have your kids anymore' it's a terrifying thing for a lot of people and there's not a lot of trust re keeping data secure"

It is clear that there is an incredibly strong mandate for the introduction of a diagnostic-code for autism and an anonymous National Primary Care Register for autism included in the Quality and Outcomes Framework (QOF) for GPs. However, it is also imperative that this is done is partnership with the autistic community, allaying their fears and promoting the benefits.

2.12 Learning from Sweden

The premature mortality statistics quoted in this report come from a Swedish study. Such a study is impossible in the UK because *we simply do not have the data available to conduct large-scale investigations of the health service use of autistic people.*

NHS Choices have acknowledged the Swedish study as highlighting a real need for a better understanding of premature mortality here in England[59].

There are limitations with using Swedish data to speak about healthcare issues in England. Our healthcare system is different, the training of our healthcare professionals is different and the management of autistic patients is different.

Autistic people in Sweden receive very early diagnosis. In Sweden, children are screened for autism at age two-and-a-half or three[60]. All diagnosed patients are recorded on the National Patient Register in Sweden. The result of early diagnosis alongside a National Patient Register is a large resource of data that can be used to monitor autistic people's healthcare and seek improvements.

The Commission welcomes the Government's commitment to launch the world's first Mortality Review for people with a learning disability. Learning about causes of premature death will help to prevent such deaths in the future. The Commission considers this to be a positive step and one which should be extended to include the premature deaths of autistic people.

A new Autism Mortality Review would begin to give a clearer picture of the mortality issues associated with autism. Without this, we remain reliant on Swedish data to speak about premature mortality and autism.

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[59] Nhs.uk. (2016). People with autism are 'dying younger,' warns study - Health News - NHS Choices. [online] Available at: http://www.nhs.uk/news/2016/03March/Pages/People-with-autism-are-dying-younger-warns-study.aspx [Accessed 17 May 2016].

[60] It should be noted that Professor Gillberg advocated for such a screening programme and argued that it ensures much earlier diagnosis. Screening for autism has been reviewed in the UK and has not been recommended. If this were to be reviewed, attention to the Swedish screening method may be helpful.

2.13 Learning from Dementia

Three key lines of our inquiry have been training, data and inspection. Strong efforts have been made to improve dementia services through training, data, inspection, awareness-raising and more. The comparison table below highlights just how far we have got to come to achieve parity for autistic people.

This comparison particularly highlights the need for investment in research. A research-spend of £4m on autism is an incongruity when the cost to the economy is £32bn[61].

	AUTISM	Dementia
Prevalence[62]	700,000+	850,000
Cost to economy[63]	£32 billion+ (based on 600,000 diagnosed)	£23 billion
Total research spend[64]	£4m	£50m
Research spend per person	£4.26[65] – £6.60[66]	£61[67]
Data	No Autism Profile No Indicator in QCF No National Audit	Dementia Profile Indicator in QCF National Audit of Dementia
Inspection	No autism-specific work undertaken by CQC	Dementia specific questions included in inspection framework
Leadership	No National Clinical Director	National Clinical Director for Dementia
Public Awareness	£325,000[68]	Prime Minister David Cameron launched 'Challenge Dementia' with a spend of £2.3m[69]

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[61] Knapp, M., Romeo, R. and Beecham, J. (2009). Economic cost of autism in the UK. Autism, 13(3), pp.317-336.
[62] ibid
[63] ibid
[64] ibid
[65] Pellicano, E., Charman, T. and Dinsmore, A. (2013). A Future Made Together. [online] newsletters.ioe.ac.uk. Available at: http://newsletters.ioe.ac.uk/A_Future_Made_Together_2013.pdf [Accessed 17 May 2016].
[66] Knapp, M., Romeo, R. and Beecham, J. (2009). Economic cost of autism in the UK. Autism, 13(3), pp.317-336.
[67] ibid
[68] UK Parliament. (2016). Autism:Written question - 36142. [online] Available at: http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2016-04-29/36142 [Accessed 15 May 2016].
[69] Theyworkforyou.com. (2016). World Autism Awareness Week - Backbench Business. [online] Available at: http://www.theyworkforyou.com/debates/?id=2016-04-28a.1573.0 [Accessed 15 May 2016].

The steps taken to improve diagnosis and support of patients with dementia have been welcome. The UK's 850,000 people with dementia deserve to have their healthcare held accountable through CQC inspections and thorough data collection. They also deserve to live in dementia-friendly communities; educated through the Challenge Dementia project. They deserve to have their condition researched with a healthy budget. They deserve to be treated by health professionals who are trained.

This inquiry has demonstrated the need for parity for autism. With significant risks posed to the health of autistic people and to their life expectancy, getting healthcare right for this population group is essential. Just like patients with dementia, autistic people deserve to have the CQC ensure that healthcare providers meet their needs. Autistic people deserve to have data collected on their condition so as to improve services, to live in understanding communities and to have their condition researched with a sensible budget. Critically, they deserve to be treated by healthcare professionals who are well-trained in their condition.

The Government's 'Challenge Dementia' programme has been transformative for patients with dementia. Steps are also being taken for autistic people but progress is slower. Our six recommendations may substantially enhance access to healthcare for autistic people.

A True Obstacle Course

COMMUNICATION DISORDER

HAVING TO SPEAK TO RECEPTIONIST WHO DOESN'T UNDERSTAND

NEEDING TO COMMUNICATE PAIN OR ILLNESS

TO A DOCTOR WHO DOESN'T EVEN KNOW YOU HAVE AUTISM

NOR UNDERSTANDS THE CONDITION OR ITS ASSOCIATE CO-OCCURRING CONDITIONS

AND RECEIVES LITTLE OR NO AUTISM TRAINING

IN AN ENVIRONMENT WHICH EXACERBATES YOUR SENSORY IMPAIRMENT

IN A SHORT, FIXED AMOUNT OF TIME WHEN YOU HAVE A PROCESSING IMPAIRMENT

THE DOCTOR TELLS YOU TO COME BACK IF IT WORSENS

BUT YOU CANNOT TELL IF IT HAS WORSENED BECAUSE YOUR SENSE OF PAIN IS UNIQUE

AND YOU FEAR THE MISUNDERSTANDING DOCTOR, THE EXPERIENCE OF THE SURGERY AND THE IMPACT ON YOUR SENSES

SO YOU DON'T GO BACK

NO ONE NOTICES ON COMPUTER SYSTEM THAT YOU HAVEN'T BEEN BACK

NO ONE CONTACTS YOU TO ENCOURAGE YOU TO SEE YOUR DOCTOR ONCE A YEAR

NO ONE ASSISTS, REMINDS OR PROMPTS YOU TO GO

NO ONE ASKS HEALTHCARE PROVIDERS ABOUT THEIR AUTISTIC PATIENTS

SO NO ONE THINKS TO ASK YOU ABOUT YOUR HEALTH

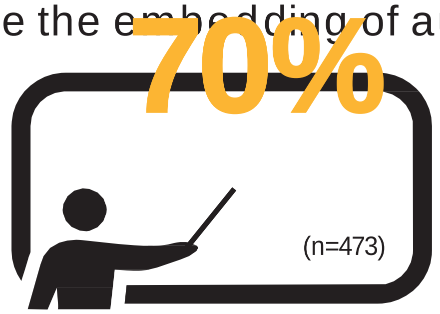
AUTISTIC PEOPLE CAN END UP WITH UNMET HEALTH NEEDS

PART THREE

RECOMMENDATIONS

3.1 Recommendation One: Training

NHS England, in partnership with autistic people, to produce a resource pack for CCGs on training; Secretary of State for Health to write to CCGS; Department of Health to strengthen Autism Self-Assessment Framework; those who control clinical curricula to ensure the embedding of autism-training.



of all survey respondents **cited training as the priority which would most improve access to healthcare for autistic people**.

The introduction of the Autism Act was a momentous achievement for the autistic community. It is the first piece of condition-specific legislation and stipulates that all healthcare staff should be trained in autism. Only 29% (down from 38% in 2013) of respondents to the autism self-assessment framework rated themselves 'green' for having training available to all[70]. There is no central collection of data on the take up of this training.

The self-assessment framework does not currently collect data on the take up of training. HEE makes training available but does not monitor the individual healthcare professionals benefitting from it. The CQC does not ask about autism training in healthcare inspections. Autism is not included in the different accountability mechanisms used for the NHS (e.g. the NHS Outcomes framework) and so NHS bodies are not incentivised in the same way as they are for learning disability and dementia to ensure that training is in place. If NHS England is going to close the health gap for autistic people, our evidence suggests it is critical that all healthcare staff are trained.

Therefore, we are calling on:

1. NHS England to produce a resource pack for CCGs with examples of best practice and advice on increasing training of all health care staff
2. Secretary of State for Health to write to all CCGs to reiterate that they are obliged to make training available as stated in the statutory guidance and instruct them to prioritise take-up of training
3. Department of Health to support existing question 19 in the Autism Self-Assessment Framework with a request for local authorities to submit data on take-up of training
4. Those in control of clinical curricula, including Health Education England, to ensure that they only commission undergraduate and postgraduate training which includes autism-awareness

Contributions made to this inquiry by autistic people and their families are clear; training, designed and delivered by autistic people, is utterly essential if access to healthcare is to be improved.

NHS England, the Department of Health, the CQC and Public Health England all must play their part in ensuring healthcare staff meet the needs of autistic people.

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[70] Improvinghealthandlives.org.uk. (2016). Autism self-assessment 2014 :: Public Health England - Improving Health and Lives. [online] Available at: http://www.improvinghealthandlives.org.uk/publications/313914/Autism_self-assessment_2014 [Accessed 14 May 2016].

3.2 Recommendation Two: Inspection

The CQC to implement five autism-specific questions into hospital and primary care inspection frameworks; include autism in Key Line of Enquiry R2; develop training guides for inspectors.

1. The CQC to include the questions on the following in their inspections framework for hospitals:
   - **a.** What reasonable adjustments do you routinely implement to meet the healthcare needs of autistic patients?
   - **b.** Which/How many members of staff have received (a) autism awareness-training and (b) specialist autism training?
   - **c.** Do you have a flag for autistic patients? If so, can you show us where they are currently?
   - **d.** Do you have an autism lead member of staff?
   - **e.** Can you show us some outcomes from the care and treatment of autistic patients?

These questions mirror existing questions for patients with a learning disability[71].

2. Key Line of Enquiry (KLOE) R2 is embedded in each inspection framework. It asks, "Do services take account of the needs of different people, including those in vulnerable circumstances?" This KLOE currently references dementia and learning disability as examples. It should be extended to mention autism.

3. A brief guide and video clip should be developed to train inspectors in an understanding of autism so that they can appropriately assess autistic people's healthcare. Health Education England should assist with this. The training should include advice on routinely including autistic people as Experts by Experience. Trainers should be equipped with an evidence table with prompts on autism. All training should be developed with autistic people and family-advocates.

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[71] improvinghealthandlives.org.uk. (2015). CQC inspection reports of NHS trusts How do they address the needs of people with learning disabilities? [online] Available at: http://www.improvinghealthandlives.org.uk/securefiles/160515_1643//IHaL%20CQC%20inspections%20LD%20FINAL.pdf [Accessed 15 May 2016].

3.3 Recommendation Three: Data Collection

GP indicator for autism in the Quality and Outcomes Framework (QOF) leading to a National Primary Care Register to end the statistical 'invisibility' of autism in the healthcare system; extension of the Learning Disability Mortality Review to include a new Autism Mortality Review.

The Commission calls for consistent diagnostic-coding to be used in GP practices so that there is consistency in flagging autistic patients. This code should be used to form an anonymous National Primary Care Register to be used to improve services, overcoming the current lack of data available. This should be introduced as part of the QOF which incentivises GPs to utilise a code and maintain a register.

95% (n=302) of autistic survey respondents **want their doctor to have a computer flag for autism**.

96% (n=297) of autistic survey respondents **would be happy to be added to an anonymous database of autistic people to help improve services**.

76% (n=241) of autistic and parent-advocate survey respondents **reported that their GP does not make changes to their or their child's services to meet their needs as an autistic service-user**.

As we do not have a clear picture of the mortality of autistic people here in the UK, we are calling for the Learning Disability Mortality Review to be extended to include an Autism Mortality Review.

An Autism Mortality Review would allow the gathering of important data into the mortality risks associated with autism. We do not currently have an accurate picture of the mortality of autistic people and as such, cannot tailor services to ensure good health outcomes.

The Commission's recommendations on data come with an intrinsically linked recommendation; discussions around the introduction of an anonymous GP register within the QOF must be had with autistic individuals and family-advocates fully involved.

...>

Some autistic people have expressed concerns about the way in which data from a GP register could be used. NICE, the British Medical Association and other involved bodies have a responsibility to work with the autistic community to ensure that their concerns are addressed and to make the benefits of such a register clear. A truly anonymous register carries far fewer concerns than one in which an individual could be identified.

We are calling for the NICE Indicator Advisory Committee to develop a GP indicator and anonymous National Primary Care register for autistic patients as part of the QOF. Furthermore, the development of an indicator for the CCG Outcome Indicator Set should be considered. The Health and Social Care Centre should develop an indicator to monitor health outcomes for autistic people in the NHS Outcomes Framework.

The National Primary Care Register would be a useful research tool. The Swedish study on premature mortality was made possible by the use of a national patient register. Consideration should be given to the use of an anonymous National Primary Care Register for autism research.

"After all, we can only be sure to improve what we can actually measure."[72]

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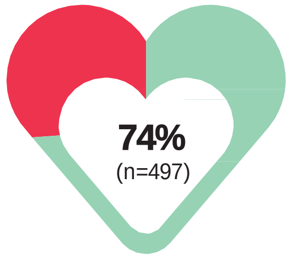
[72] gov.uk. (2008). High Quality Care For All. [online] Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/228836/7432.pdf [Accessed 15 May 2016].

3.4 Recommendation Four: Annual Health Checks

Following the introduction of an anonymous National Primary Care register for autism within the QOF, NHS England should look to implement annual health checks for autistic people.

On the basis of health inequalities suffered by those with a learning disability, annual health checks for people with a learning disability were introduced in 2008/09. Annual Health Checks are seen to be a reasonable adjustment.

According to the Swedish study, autistic people who do not have a learning disability die an average of 12 years prematurely yet we do not offer this population group an annual health check.

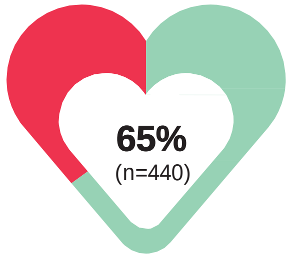


of all survey respondents **feel that autistic people received 'worse' or 'much worse' healthcare compared with non-autistic people**.

There is a good evidence to show that the introduction of health checks consistently leads to:

- "the detection of unmet, unrecognised and potentially treatable health needs (including serious and life threatening conditions such as cancer, heart disease and dementia)
- Targeted actions to address these health needs"[73]

The evidence gathered for this inquiry indicates that the whole autistic population may benefit from an annual health check.



of all survey respondents **felt that health professionals 'rarely' or 'never' understand autism and how it affects someone's physical and mental health**. A full health check is a reliable way of identifying and treating co-occurring conditions.[74]

Part of the reasoning for introducing annual health checks for people with a learning disability, was the recognition that people with learning disabilities often have "difficulty in recognising illness, communicating their needs and making timely use of primary health care services"[75]

...>

A core symptom of autism is difficulty in communication. Furthermore, autistic people do not experience pain and other symptoms in the same way as the neuro-typical population and their ability to make timely use of healthcare services may therefore be impaired. There is also a common theme from our consultation which shows autistic people avoiding healthcare settings and lacking the motivation, inertia and ability to make timely use of primary health care services. The co-occurring conditions of anxiety and sensory impairment exacerbate these problems.

It has also been noted that the learning disability annual health checks are beneficial because they are an 'introduction' to the GP and the surgery environment. This familiarisation process is critical for autistic people who appreciate predictability. Yet autistic people are not offered this introduction. Such an opportunity would decrease uncertainty which is a key driver of anxiety which in turn, may be a cause of avoidance behaviours.

The introduction of such checks should be done in consultation with the autistic community to ensure they are accessible, take-up is good and they are effective.

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[73] Robertson, J., Roberts, H. and Emerson, E. (2010). Health Checks for People with Learning Disabilities: A Systematic Review of Evidence. [online] improvinghealthandlives.org.uk. Available at: https://www.improvinghealthandlives.org.uk/uploads/doc/vid_7646_IHAL2010-04HealthChecksSystemticReview.pdf [Accessed 15 May 2016].
[74] ibid
[75] ibid

3.5 Recommendation Five: Leadership

NHS England to appoint a National Clinical Director for Autism and an autism-lead member of staff; health bodies to appoint autism-lead staff; Department of Health to include autism in Public Health England's Remit Letter.

Autism is not only statistically invisible within the health system but is also an underrepresented condition. There is no National Clinical Director for autism within NHS England nor an autism 'lead'. Furthermore, there is no autism lead in the Royal College of Nursing, Royal College of Paediatrics and Child Health or Royal College of Psychiatrists, nor in Public Health England, NHSCC, CQC, NICE or any other NHS or arms-length body that the Commission is aware of. There are no autism nurses on hospital wards and very few autism liaison staff in GP surgeries.

This lack of leadership leaves gaps in ensuring that health services meet the needs of autistic patients. Rarely is there an autism-specific approach which avoids this fragmentation.

This lack of leadership has been identified by professionals and autistic people alike. Hazel Watson, NHS England, explained that although there is a commitment in the NHS mandate to reduce health inequalities for autistic people, because implementation sits across a number of programmes, it is harder to follow a 'Golden Thread' to ensure delivery.

The Commission calls on the Department of Health to request NHS England to appoint a National Clinical Director for Autism and an autism-lead to work in partnership with the autism-lead in the Department of Health and to oversee:

- production of a 'Golden Thread' implementing work-streams from the NHS Mandate to NHS Business Plan
- appropriate introduction of an Autism Indicator in the QOF for GPs and a Primary Care Register for autism
- timely introduction of annual health checks in consultation with the autistic community
- production of a resource pack for CCGs, in partnership with autistic people, to ensure that autism-training becomes embedded
- the Government's call to reduce health inequalities
- liaison with bodies such as HEE and General Medical Council to ensure that the healthcare workforce can meet the physical and mental health needs of autistic people
- cessation of the hospitalisation of healthy autistic people
- cessation of inappropriate use of Assessment and Treatment Units.

The Department of Health's remit letter to Public Health England does not mention autism. The Remit Letter should reference the need to collaborate on closing the health gap for autistic people.

3.6 Recommendation Six: Resources

Department of Health to launch a time-limited Autism and Health Innovation Fund.

75% (n=510)

of autistic and parent-advocate survey respondents said that they **would like to receive help to understand what will happen when they go to the doctor or hospital**.

The Asperger Consultant Group explained in their submission to the Commission, the importance of their concept of the Triad of Understanding – 'others understanding me', 'me understanding myself' and 'me understanding others'. It is critical to train health professionals to understand autistic individuals. However, it is also critical that autistic people are able to understand themselves and others too. Autistic people may need to be helped understand their own symptoms, where to go for help, how to ask for help, what the process will be and what the outcomes might be.

The myVoice Youth Consultants, a group of young autistic people, have been reviewing local health services with a grant from the Department of Health. One of their key recommendations is that service providers should produce and distribute information to patients so they understand how to use the service in a step-by-step format.

The 'All About Me!' pilot project, funded by NHS England and produced by Autism-In-Mind, wrote to the Commission and told us "…we believe that if young people have greater self-awareness and a developed understanding of what their autism means to them; they will be better equipped to deal with life stressors…If you don't have a good understanding of self…then how can you go to the doctors with a healthcare need and be sure it is a healthcare need and not just related to your autism?"

- We are calling for the Department of Health to offer a time-limited Autism and Health Innovation Fund.
- Applications to be made by Royal Colleges, NHS bodies and third sector organisations.
- The scope of the fund is for the development and distribution of tools, aids and resources to help autistic people make the most out of healthcare experiences.
- Research funders should also consider studies into preventing poor health in autistic people. Such research may prove a useful tool in indicating which resources/aids/mentoring programmes autistic people would benefit from.

The National Autistic Society has developed a hospital passport which is currently undergoing review. Only 4% of our survey respondents use the hospital passport but 30% said they would like their GP to provide one to them. If the review concludes that this is a worthwhile tool, raising awareness of its availability and training healthcare professionals to use it, will be important.

Understanding is a two-way process. As professionals are trained, autistic people should be equipped with the resources to understand what will happen in healthcare environments.

"We have nothing, to help us, last time I had to attend hospital for a emergency op they wouldn't take my needs into consideration and I refused to stay and went untreated"
Mary Croos, Self- dvoate

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[76] Robinson, J. (2016) 'Data analysis in participatory research with adults with Asperger's syndrome' in Hardwick, L, Smith, R. and Worsley, A. (eds.) Innovations in Social Work Research, Jessica Kingsley, pp. 241-258

These six, simple, inexpensive and achievable recommendations could substantially improve access to healthcare for autistic people. The recommendations could help to make steps towards closing the health gap suffered by autistic people and improve quality of life and life expectancy.

Training, inspection, data collection, annual health checks, leadership, resources and research are the tools to deconstruct the obstacle course.

Acronyms

DHD	Attention Deficit Hyperactivity Disorder
PPG	All Party Parliamentary Group
AS	Asperger Syndrome
SC/ SD	Autistic Spectrum Conditions/Autistic Spectrum Disorders
CPD	Continuous Professional Development
CQC	Care Quality Commission
GP	General Practitioner
HEE	Health Education England
IQ	Intelligence Quotient
KLOE	Key Line of Enquiry
LA	Local Authority
LD	Learning Disability
LGBT	Lesbian, Gay, Bisexual and Transgender
MHMDS	Mental Health Minimum Data Set
NHS	National Health Service
NHSCC	NHS Clinical Commissioners
NICE	The National Institute for Health and Care Excellence
PHE	Public Health England
QOF	Quality and Outcomes Framework
RCGP	Royal College of General Practitioners
RCN	Royal College of Nursing
RCPCH	Royal Colleges of Paediatrics and Child Health
RCPsych	Royal College of Psychiatrists
S F	Self-Assessment Framework

Acknowledgements

The Westminster Commission on Autism is extremely grateful to all Members of the Commission for their input and support. Special thanks must go to:

Asperger Consultation Group

Craig Kennady

Dame Stephanie Shirley

Dean Milner-Bell

Deborah Evans

Dr Carole Buckley

Dr Damian Milton

Dr Michael Sills

Helen Ellis

Jonathan Andrews

Katie Thrower

Rory Graham

Susan Dunne

Xanthe Shacklock

We would like to express our thanks to the Shirley Foundation for generously sponsoring the production and printing of 1000 copies of this report.

Appendix One: A Note on Diagnosis

According to respondents in the ASPECT report, a national consultation of those with Asperger Syndrome, diagnosis was a key area of concern; 64% (n=154) of respondents said it was either very or somewhat problematic to get a diagnosis and 61% (n=145) find the route to diagnosis very difficult.

Autistica's 'One in a Hundred' report noted that families found getting a diagnosis a real challenge and did not feel that they received sufficient information and services .

While diagnosis is an issue of great concern to the autistic community and their families, the Commission recognised the existing work being done by the All Party Parliamentary Group on Autism in partnership with the National Autistic Society. The Commission welcomes the Government's commitment to measure the number of people diagnosed with autism in every area of England. In an effort to avoid replicating existing work, the Commission did not include a specific focus on diagnosis in the Terms of Reference for this inquiry.

However, it should be noted that the Commission sees diagnosis as a critical aspect of access to healthcare. The recommendations made here cannot be successfully implemented without due attention to the diagnosis crisis facing our country. More about the crisis can be seen at www.autism.org.uk/DiagnosisCrisis

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[77] Beardon, L. and Edmonds, G. (2016). ASPECT Consultancy Report. [online] sheffield.ac.uk. Available at: https://sheffield.ac.uk/polopoly_fs/1.34791!/file/ASPECT_Consultancy_report.pdf [Accessed 14 May 2016].

[78] Wallace, S., Parr, J., and Hardy, A. (2013). One in a Hundred: putting families at the heart of autism research. [online] autistic.org.uk Available at: https://www.autistica.org.uk/wp-content/uploads/2014/10/One-in-a-Hundred-Autisticas-Report.pdf

Appendix Two: Inquiry Terms of Reference

The Westminster Commission on Autism

Access to Healthcare Inquiry - Terms of Reference

The Westminster Commission on Autism has been launched in recognition of the need to do more to work in strategic partnerships, taking action to improve quality of life for people with autism. All work carried out by the Commission will be driven by the authentic voices of those with autism and their families/advocates. The Commission will produce evidence based recommendations for policy and practice. The Commission will meet regularly in the Houses of Parliament and hold time-limited inquiries. These inquiries are intended to lead to positive improvements in policy and practice.

Following the Government's inclusion of tackling health inequalities and promoting "full, healthy and independent lives"[79] for people on the autism spectrum in the latest mandate to NHS England, the first inquiry will consider 'Access to Quality Healthcare' for people on the autism spectrum. The inquiry will make specific reference to recent studies indicating that people on the autism spectrum die prematurely in almost all 'cause-of-death' categories[80]. The Commission recognises timely access to healthcare, including preventative care, as an essential part of ensuring that autistic people live long and healthy lives. Further, the Commission holds that good autism practice is good practice for all.

Therefore, the 'Access to Quality Healthcare' inquiry will seek to answer the following key questions:

1. What barriers are present when people with autism access healthcare services?
2. In seeking to address the barriers, what is the role of training in finding solutions? This includes staff in healthcare environments as well as training for people with autism to equip them to make the most of their healthcare services.
3. In seeking to address the barriers and improve quality of life and life expectancy, what is the role of data collection, regulation and inspection?
4. What more can be done to improve implementation of existing measures/resources (i.e. NICE guidelines) which are aimed at addressing the barriers?

The Commission will call for evidence submissions from autistic people, their families, charities, service providers, academics, health professionals, statutory bodies and others. Themes drawn from this evidence will be used to produce recommendations in a written report for the attention of Government, NHS England, Clinical Commissioning Groups, Local Government and others. If it is felt that new measures/resources are required to address the issues uncovered, the Commission may choose to run a follow-up inquiry. All work carried out by the Commission is aimed at creating a more 'autism-friendly' world so as to improve quality of life for people with autism.

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[79] Gov.uk. (2016). The Government's Mandate to NHS England for 2016-17. [online] Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/494485/NHSE_mandate_16-17_22_Jan.pdf [Accessed 15 May 2016].
[80] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P. and Bolte, S. (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), pp.232-238.

The Surgery

She tries to hide her grimace with a smile
Sickly and feigned – but thinks I cannot tell –
And gestures, still confused, to velvet chairs.
"You'll need to sit and wait" she clarifies,
Her furrowed brow betraying silent hope
I pick the one that's furthest from her desk.

"So what's this all about?" His crocodile-
fanged mouth demands an answer briskly snapped.
I start composing thoughts; he chomps again,
Incisors devouring my blooming thoughts.
Too much light gnaws their weeds; the ceiling glares;
The muggy heat constricts my gasping throat.

I've never told him. But he's never asked;
"Physician, educate thyself", I say.
The nurses used to grasp it all, until
Cost-cutting saw them shunted out the door.
"There's not much I can do". He falsely smiles.
"Come back if it gets worse, that's what I'd do".

I still recall that day ten years ago.
Sometimes I wonder if I should go back –
But surely they would tell me if I should?

By Jonathan Andrews, Self-Advocate


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ADDING VALUE TO LIVES
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AUTISTICA
RESEARCH AUTISM
NCG NATIONAL CHILDREN'S GROUP
mind
for better mental health
The National
Autistic Society
Ambitious about Autism
Hesley Group
north east
autism society