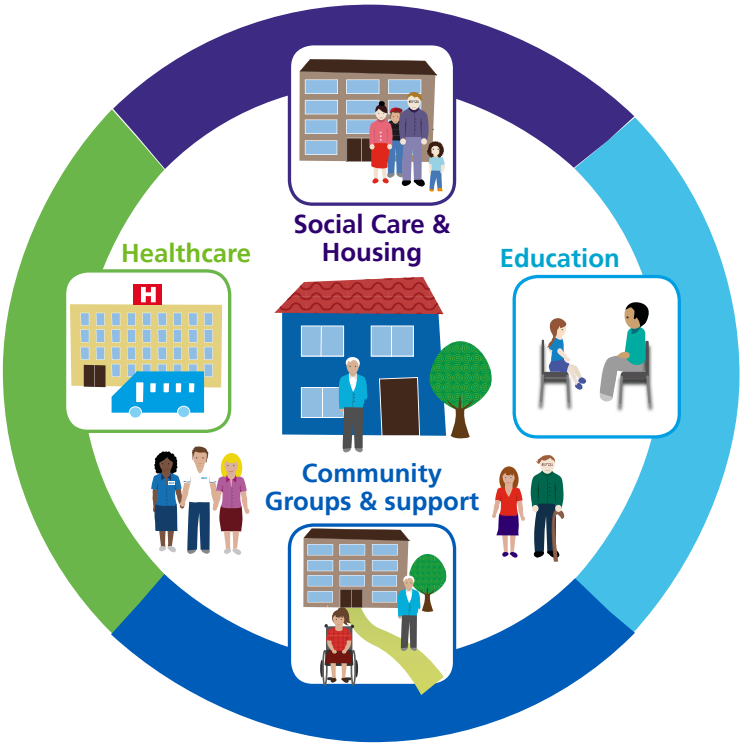
One Gloucestershire
Transforming Care, Transforming Communities

Learning Disability & Autism

#YourVoiceMatters

Learning Disability & Autism Strategic Needs Analysis

A report to find out what is important to people living with a learning disability or autism in Gloucestershire.



2018-2019

Learning Disability and Autism Strategic Needs Analysis #YourVoiceMatters

The following report is the product of a co-produced piece of work contributed to by the Learning Disability and Autism Partnership Boards, The Learning Disability & Autism Clinical Programme Group, Gloucestershire County Council and Inclusion Gloucestershire.

The report has been titled #YourVoiceMatters because **only** the people who have a learning disability, autism (or both) and/or those that care for them know what works for them. This information alongside analysis of data will help commissioners and Partnership Boards show what's working well and what needs to change in future in health and social care.

It is the first time in Gloucestershire that we have attempted to draw together a range of qualitative and quantitative data to begin to establish the prevalence, needs, views, opinions and individual strengths of adults with a range of conditions traditionally categorised as learning disability.

This report represents the first phase in developing a better understanding of this diverse group, includes key findings and a range of recommendations for further work, including further exploration of the factors contributing to individual resilience and self care. Many of these recommendations will now be taken forward by the Partnership Board and Clinical Programme Group. The report will also help inform the Council & Clinical Commissioning Group's strategic thinking.

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Summary - what we have learned about Learning Disabilities in Gloucestershire

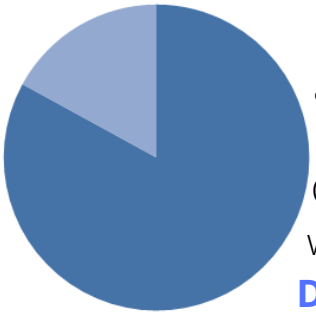
11,746

We think that around 11, 746 people in **Gloucestershire** aged between **18-64** have a **Learning Disability**.

We think that by the year 2035, there will be around **100 more** people in Gloucestershire with a Learning Disability.

11,820

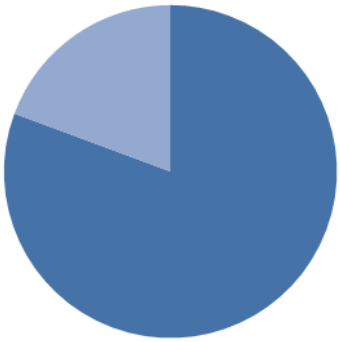
11,746



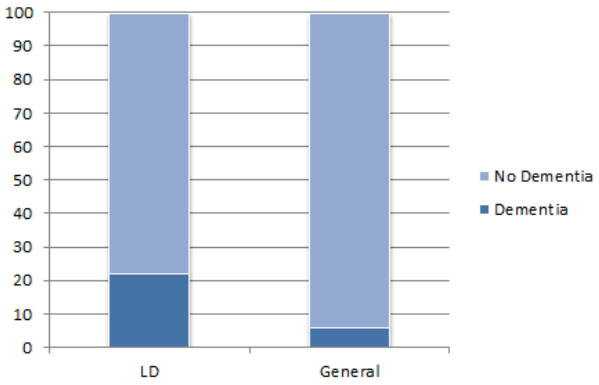
2,412

We think that around 2412 of the people in Gloucestershire with a **Learning Disability** have a **moderate** or **severe** disability.

We think that around 2816 of the people in Gloucestershire with a **Learning Disability** are **aged 65 or over**.



2,816



We found out that **Dementia** is more common in people with a Learning Disability. **22%** of people with LD aged 65+ had dementia, compared to **6%** of people over 65 without an LD

EXECUTIVE SUMMARY - #YourVoiceMatters

Introduction

This report aims to develop our understanding of broad areas of life for people with Learning Disability and/or Autism in Gloucestershire. A co-production approach was adopted for this piece of work which set the parameters for the range of issues considered and included. It will be used to inform our strategic thinking which in turn will support people to live as independent and healthy lives as possible. It brings together quantitative data from a range of sources and qualitative experiences through a range of engagement groups including the Learning Disabilities Partnership Board, The Learning Disabilities Health Action Group and a range of engagement sessions which were run by Inclusion Gloucestershire[1].

The original scope of the work was to adopt an all-age approach and be inclusive of the wide range of conditions and needs which people with a learning disability and or autism may have.

The following report summarises key findings and highlights a number of recommendations which can be progressed through the Learning Disability & Autism Partnership Boards, Clinical Programme Group (CPG), Gloucestershire County Council (GCC) and other partner organisations.

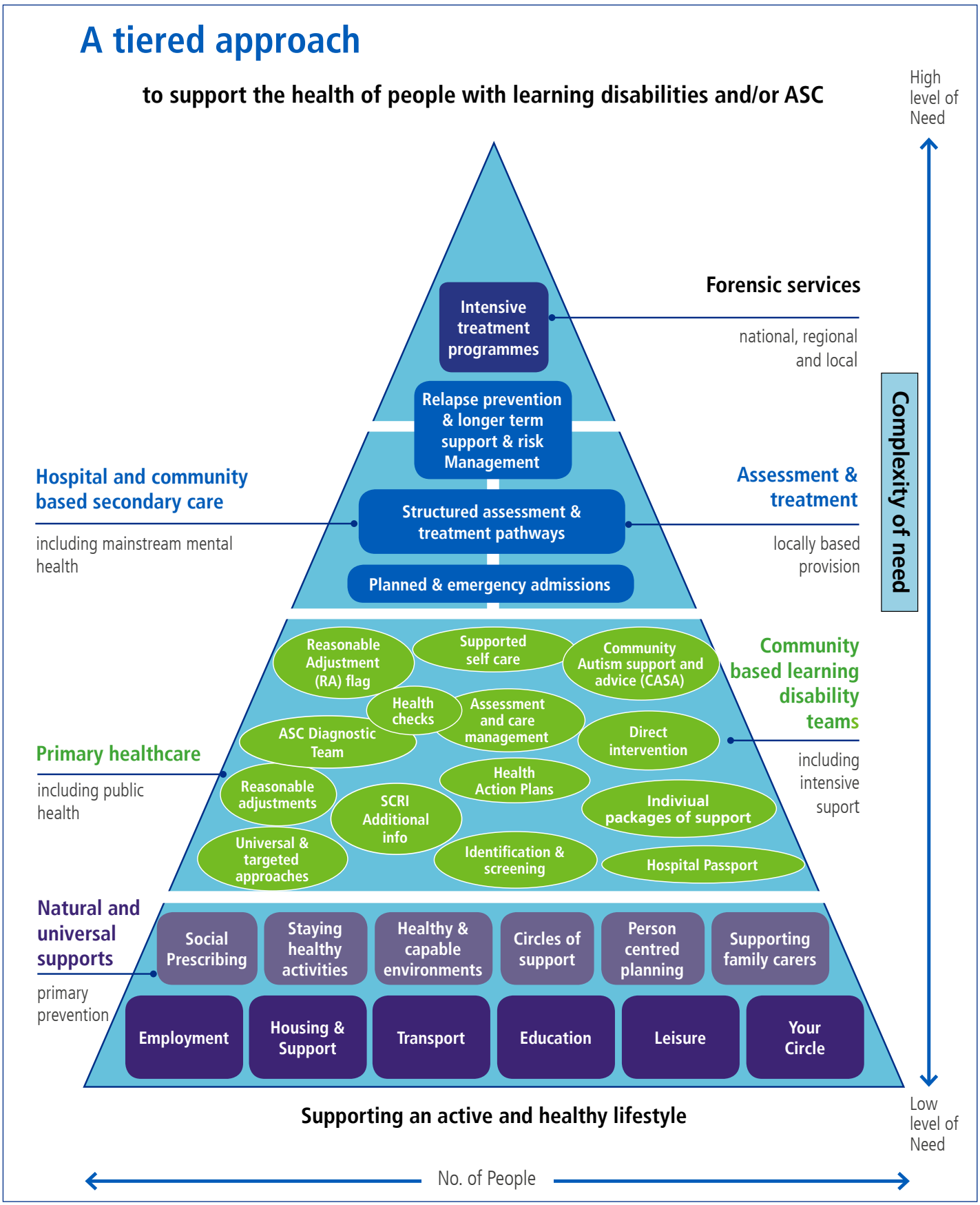
Some of the challenges include to:

- Effectively manage resources, as higher life expectancy due to further medical advances means that people are living longer with more complex needs, increasing the demand for services and support.
- Do more with less and create opportunities to work more collaboratively and creatively with partner agencies, third sector organisations and communities.
- Develop the market to enable greater choice and more flexible, sustainable models of care and support.
- Operate in a more person-led way to develop independent living options and maximise the resilience of people.

[1]Gloucestershire Health & Care NHS Foundation Trust – 4 me about me, – LD Expert Reference Group

Building a picture of need in Gloucestershire

Figure 1 - A tiered approach to support the health of people with learning disabilities



This report highlights that:

- The population estimates of people with a learning disability in Gloucestershire (18 - 64) is currently estimated as 11,746[2], this is expected to rise in 2035 to 11,820 (0.8% increase).
- Approximately 4,918 adults in Gloucestershire are predicted to have Autistic Spectrum Conditions (ASC) in Gloucestershire. This is expected to rise in 2035 to 5,560 (13% increase). A quarter of this population are predicted to be aged 65 years or older.
- 1,850 adults with ASC are known to Primary Care.
- Approximately 11,746 adults in Gloucestershire have a learning disability; 2,412 of these adults have a moderate or a severe learning disability and 2,816 are aged 65 or over.
- The population estimates of people with a learning disability in Gloucestershire (65+) is currently estimated to be 2754[3], this is expected to rise by 2035 to 4,118 (50% increase).
- The prevalence of dementia is higher amongst older adults with learning disabilities compared to the general population (22% vs 6% aged 65+).
- There are 1,451 children aged between 7-15 identified in schools with learning disabilities and/or ASC. The greatest proportion of these children, live in Gloucester.
- 37% of children aged 4-18 identified with learning disabilities or ASC come from the most deprived communities compared to 21% in the general school aged population; therefore there is a 16% health inequality gap.
- 10.6% of permanent school exclusions during 2016/17 had identified learning disabilities and ASC needs.
- 1,114 children with a learning disability are placed in special schools with a further 19 placed in residential schools (10 in county, 9 out of county).
- Data sources indicate that people with a learning disability predominantly live in Gloucester and Cheltenham and population projections indicate this will be where most people with learning disabilities will live in the future.

[2] Projecting Adult Needs and Service Information System (PANSI)
[3] Projecting Older People Information System (POPPI)

Key Recommendations

The Learning Disability & Autism Partnership Boards' & Clinical Programme Group will own and prioritise the recommendations (this is fully listed in Appendix 5), develop a plan and work with partners to progress the subsequent actions. **A key recommendation is that there is a review of the Partnership Boards and Clinical Programme Group to ensure consistent approach strong governance and a single plan.**

Specifically the plan should include the recommendations in relation to

- Access to services
- Mainstream and specialist health services
- Support to access education, employment and volunteering opportunities
- Support around social care and housing

This report has highlighted many areas where further work is required and provides a foundation for this work to develop. The co-production approach has ensured that areas of life important to this diverse group of people have been included which may not have been the case with a traditional quantitative approach. A key strength of this collaboration has been the numbers and range of stakeholders engaged throughout with whom we are able to continue the dialogue to inform our strategic thinking. **A key recommendation is that co-production is embedded as a key enabler to re-designing and further developing services.**

Improved pathways to access services has repeatedly come up during this engagement process, specifically around timely access to diagnostic services, reasonable adjustments being utilised and considered by providers and access to easily accessible information from a single point of access. **A key recommendation is that diagnostic services are meeting NICE standards.**

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Learning Disability & Autism Strategic Needs Analysis

2018-2019

CHAPTER 1 –

Introduction

1. Introduction

This report aims to develop our understanding of broad areas of life for people with learning disabilities and/or Autistic Spectrum Conditions (ASC) in Gloucestershire.

The report begins to identify:

- Population trends and growth.
- The current and likely future demands on services.
- People's experience of a range of support and services.
- Where we could make improvements in the future.

The report was co-produced with Inclusion Gloucestershire, members of the Learning Disability Partnership Board, the ASC Partnership Board and other people with "lived experience", in order to gain a more holistic view.

Qualitative data was captured through:

- a survey (appendix 1),
- 17 open events and 24 focus groups/ engagement events (5000 people's views were captured as part of this process), some of whom access Gloucestershire County Council (GCC) social care services and Gloucestershire Health & Care NHS Foundation Trust specialist services. (appendix 4)

The needs analysis brings together quantitative data from a range of sources (appendix 2 and appendix 3). The report presents key findings and a range of recommendations for the ASC and Learning Disability Partnership Boards & Clinical Programme Group, GCC and partner organisations. Its aim is to inform strategic thinking which in turn will support people to live as independently as possible in line with the priorities already defined within GCC Building Better Lives Strategy (2014) and the NHS Long Term Plan (2019).

1.1 Key Drivers

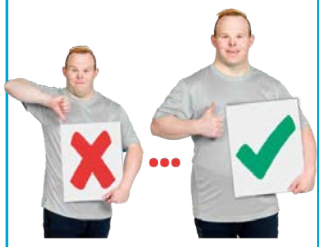
Key Drivers	Outcomes	Working Together
• Transforming Care • 5 Year Forward View • Care Act 2014 • NICE Guidance • Housing for Care • Prevention Concordat for Better Mental Health • Future in Mind • Mental Health Act • Mental Capacity Act and DOLS • Think Autism • OFSTED and CQC • Time to Change • Integrated Personalised Commissioning (IPC) • Building Better Lives • Transforming Care Plan • Autsim Strategy • Co-Production Charter • Joint Strategic Needs Assessment (JSNA) • Adult Single Programme and 3 Tier Conversation • Sustainability and Transformation Plan • Mental Health and Wellbeing Strategy • Mental Health Crisis Care Concordat	Effectively resourced so people can • Receive early help and co-ordinated whole life approach • Be included, independent and experience Personalisation through choice and control • Contribute to and have shared responsibility for their lives • Leading fullfilling lives with barriers to this removed	• Co-production • Partnership Boards • Clinical programme groups

There are a number of national policies impacting on this area of work; most significantly:

	Local / National	Driver	Description
	**National**	**NHS England – 10 Year Plan 2019-2029[1]**	**Tackling preventable deaths: stopping overmedication and improving health checks** • Health checks in primary care will be improved in both uptake and nature, with the aim of reaching 75% of people aged 14+ with a learning disability annually. Hearing, sight, and dental checks will be given to young people in residential schools. • Initiatives such as STOMP-STAMP will be supported locally. • The Learning Disabilities Mortality Review Programme (LeDeR) will continue, with the aim of improving the lives of people with learning disabilities nationally. **Improve understanding of learning disabilities and autism within the NHS** • NHS staff will receive training about how to best support people with learning disabilities and autism. • Over the next five years, national learning disability improvement standards will apply to every NHS-funded service. By 2023/24, a "digital flag" in patient records will signify to staff that someone has a learning disability or autism. Locally, we are involved in the pilot for testing this which commenced in April 2019. **Reduce waiting times for specialist services** • The long waiting times for diagnostic assessments for children and young people suspected as being autistic is highlighted. Indeed, the next three years will see autism being included alongside mental health services to achieve timely assessments. • By 2023/24, children with the most complex needs will each have a designated keyworker to ensure that they are being best supported. **Increase investment in community support: reducing inpatient admissions** • Specialist Inpatient Numbers within the TC Programme to reduce down to 23 people during 2019-20 and to 15 by 2020-2021 which will be supported by 7 day crisis care in the community via LDISS. • Post diagnostic support for those with autism - Community Advice and Support for Autism (CASA) Service providing a post diagnostic support pathway for individuals with autism spectrum conditions (ASC). The aim is to help individuals to understand their diagnosis and manage the implications of living day to day with ASC. The service commenced on April 1st 2019 for 5 years and is being delivered by the Independence Trust. **Improve quality of inpatient care across NHS and independent sector** • Implement and be monitored against a "12-point discharge plan" to ensure discharges are timely and effective.

[1]https://www.longtermplan.nhs.uk/

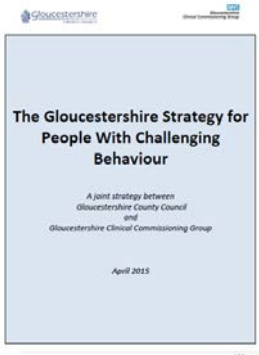
	Local	**Integrated Care System (ICS) Plan**	The priorities listed below are equally applied to those with a learning disability with or without autism; 1. People taking greater control of their own health. 2. Healthy, active communities with strong networks of support. 3. A simpler way to get advice, support and services. 4. Vast majority of care in or near home. 5. High quality joined up services with the right care, staff skills and equipment in the right place. 6. Best use of the "Gloucestershire pound" for health and wellbeing priorities. 7. The best professional support and learning development opportunities for our staff in great working environment
	**National**	**Transforming Care - Building the Right Support (2015)**	Forty eight transforming care partnerships (TCPs) have been created nationally to develop three-year plans to re-shape services, to meet local needs. Gloucestershire County Council and Gloucestershire Clinical Commissioning Group, along with its partner organisations, make up Gloucestershire "Transforming Care Partnership" (TCP) Developed jointly by NHS England, the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS) – with active input from people who use the services and their families – its aim is to enable people with learning disabilities and/or autism to live more independent lives in the community, with appropriate support and closer to home. Gloucestershire's Transforming Care Plan sets out the aims to improve life opportunities for people with a learning disability and/or autism and is based on a strong understanding of the needs and aspirations of people with a learning disability and/or autism, their families and carers, and on expert advice from clinicians, providers and others. The plan highlights areas of strategy development and service delivery that is currently taking place across the TCP area. The strategy developments and service delivery areas are considered opportunities for learning and good practice sharing and serve to strengthen the overall TCP plan. People with a learning disability and/or autism should be able to access **specialist health and social care support in the community** – via specialist multi-disciplinary health and social care teams who work in close partnership, with that support available on an intensive 24/7 basis when necessary. With the right set of services in place in the community, the need for inpatient care will significantly reduce and commissioners will need to have in place far less hospital capacity.

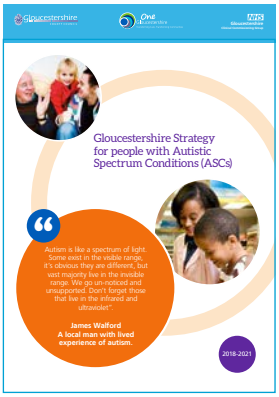
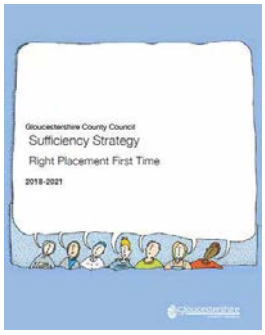
	**National**	**NHS Improvement Learning Disability Standards[2]**	To promote greater consistency. Rights, the workforce, specialist care and working more effectively with people and their families are illuminated as key themes. Locally, NHS providers have submitted a self assessment to NHS Improvement. This benchmarking is being undertaken nationally and the feedback from this is expected shortly. By 2023/24, all care commissioned by the NHS will need to meet the Learning Disability Improvement Standard, with a particular focus upon seclusion, long-term segregation and restraint. Locally 2Gether NHS Foundation Trust have participated with Care Quality Commission (CQC) to undertake a thematic review of this.
 	**National**	**Learning from Deaths (LeDeR)**	The LeDeR Programme (Learning from Deaths review of people with a learning disability) is being led by the University of Bristol and follows on from the Confidential Inquiry into Premature Deaths of people with LD (CIPOLD) the findings of which demonstrated that on average someone with a LD lives 20 years less than someone without. Further information about the LeDeR Programme is available on the University of Bristol Website[2] LeDeR Annual Report. The issues and causes of death identified within the national LeDeR annual report (published May 2018), alongside the findings from locally completed local reviews reflect the many challenges that people with a learning disability face. There is much work already underway nationally and locally to improve access to healthcare and to address inequality for people with a learning disability. Through the development of new tools to support practitioners, and new resources to develop skills and awareness, we are creating a culture within health and social care of improved access, and vigilant and proactive support for people with a learning disability. But there is clearly more to do.
	**National**	**National Institute for Clinical Excellence (NICE) Guidelines[3]**	NICE is the short name for the National Institute for Health and Care Excellence. NICE find out what works well in health and social care and write advice about it. The advice says what care and support people using services should have. Doctors, nurses, care workers and support workers should know what NICE says. It helps them give good care and support. People using services and their families, carers and advocates should know what NICE says too. It can help them get the right care and support.

[2]https://improvement.nhs.uk/documents/2926/v1.17_Improvement_Standards_added_note.pdf
[3] http://www.gloucestershireccg.nhs.uk/wp-content/uploads/2019/12/LeDeR-annual-reportPresscopy_October19.pdf

 	**National**	**Mental Health Act, Mental Capacity Act 2005 & Liberty Protection Safeguards (2018)**	The Mental Health Act is a law that tells people with a mental health disorder what their rights are and how they can be treated. The term "mental health disorder" is used to describe people who have: • a mental illness • a learning disability • a personality disorder Being detained (also known as sectioned) under the Mental Health Act is when you are made to stay in hospital for assessment or treatment. The Mental Capacity Act 2005 is a law that affects people age 16 or over, who are not able to make decisions for themselves. It includes rules that order people to be looked after safely who cannot make decisions for themselves. It gives rights to people who cannot make decisions for themselves. People have the right to have an independent mental capacity advocate.
	**National**	**Skills for Care: Learning Disabilities Core Skills Education and Training Framework (2016)[4]**	Provides a framework for education and key skills development for those who are caring for people with a learning disability.
    	**National**	**IHAL Determinants of Health Inequalities (2013)**	This document describes the factors contributing to health inequalities. They fall into 5 broad areas: a) Social and economic. Living and working conditions/ social and community relationships. b) Constitutional factors. Personal biology/genetics/ physical and mental health conditions. c) Communication difficulties and lower levels of health literacy. d) Personal health behaviours, Behavioural and Lifestyle factors. e) Deficiencies in access to healthcare and related services. Encouraging **Active Individuals and Active Communities** to support people to stay as healthy and as independent as possible. However much help is available from family, friends, neighbours and communities, we know there will always be some people who will also require social care services.

[4]http://www.skillsforhealth.org.uk/images/resource-section/projects/learning-disabilities/Learning-Disabilities-CSTF.pdf

	**National**	**Changes to benefits system**	The changes in the benefits system from **Disability Living Allowance** to the **Personal Independence Payment and more recently to the Universal Credit;** has increased the eligibility criteria for people with disabilities to access benefits, which may in turn increase demand on health and social care services.
	**Local**	**Gloucestershire's Building Better Lives Policy 2014-2024**	The all age, all disability vision of the and its seven core principles; **1**. Early help. **2.** Inclusion. **3.** Independence. **4**. Contribution. **5.** Shared responsibility. **6**. Personalisation through choice and control. **7.** Coordination of a whole-life approach.
	**Local**	**Gloucestershire's Challenging Behaviour Strategy**	The purpose of the Challenging Behaviour Strategy is to provide clear direction, shared outcomes and values to all who contribute to supporting people with challenging behaviour. A joined-up approach and shared vision is key to making the best use of the skills and resources in Gloucestershire. The definition of challenging behaviour is as follows: 'Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.' Emerson 1995. As this strategy was prompted by the government's recommendations in relation to Winterbourne View, its current focus is on people with learning disabilities.

			Its objective is to commission a capable and confident spectrum of support and services to meet the range of requirements which children and adults with challenging behaviour present. In doing so we want people who present with behaviour that is challenging to achieve the following outcomes: • To live locally and in their community. • To lead meaningful lives where they enjoy being included in society and have the opportunity to access employment and develop skills. • To maintain strong links with friends and family who feel confident in supporting them. • To be supported by competent providers. • We aim to create a sufficiently supportive system for the individuals, their families and their providers to work preventatively and manage down behaviour; avoiding placement breakdown, escalating costs, reliance on increasingly specialist services and unnecessary admission to inpatient units.
	**Local**	**Gloucestershire's Autism Strategy (2018-2021)**	"Think Autism", the National Strategy, places an expectation on local councils and health services to develop plans to ensure that people with ASCs who live in their area get the help that they need. Gloucestershire's Autism Strategy responds to that expectation. In Gloucestershire a multi-agency ASC Partnership Board oversees the Autism Strategy. The first local strategy covered the period 2013 – 2016 and focused on adults with autism. The new strategy covers the period 2018 – 2021 and supports children, young people and adults. Gloucestershire is working to a ten-year policy (2014 – 2024) called "Building Better Lives", which has an all age, all disability approach. In line with this policy, the Autism Strategy sets out future priorities for people with ASCs of all ages in Gloucestershire. Click the link to read the strategy: Gloucestershire Autism Strategy 2018-2021 (PDF, 1.9 MB)
	**Local**	**Gloucestershire's Sufficiency Strategy – Right Placement First Time 2018-2021**	Gloucestershire's Sufficiency Strategy sets out how we propose to reconfigure our services to meet current and future needs of the children, young people and their families who are reliant on our support. For children and young people with learning disabilities and autism the strategy includes: • Short breaks for children with additional needs. • Respite and Shared Lives services for Children with Disabilties. • Increase in-house fostering capacity for respite carers and those who require intensive support. • Multi Agency Resource Panel and Transition Panel. • Positive Behavior Support Model Social Impact Bond.

National

Care Act 2014 and the Children and Families Act 2014

The Care Act is the biggest change in Adult Social Care in over 60 years. It combined many previous laws into one new law which has a greater emphasis on:

- wellbeing and prevention.
- making sure that people have the information and advice they need to make good choices about care and support.
- meeting care and support needs of adults and their carers – rather than an emphasis on providing services.
- carer rights – including the rights for young carers who are providing care and support to an adult.
- provisions apply to both people in need of care and support and to carers.

The Care Act also introduced:

- national care and support eligibility criteria for both adults and carers.
- rights to independent advocacy in some circumstances.
- personal budgets and rights to request a direct payment
- new responsibilities about:
- making the transition from children's services to adult social care.
- provider failure, for example if a care home closes.
- supporting people who move between local authority areas.
- Find out more about safeguarding on the Gloucestershire Adults Safeguarding Board (GSAB) website.

The Children and Families Act 2014 is a landmark and wide-ranging act designed to fully reform services for vulnerable children, by giving them greater protection, paying special attention to those with additional needs, and also helping parents and the family as a whole.

This summary outlines the key changes the Act made to the safeguarding and child protection system and services for children and families. Although incorporated into one single Act, due to the extent of the changes made, many elements came into force at different times, with most by the end of 2015. https://www.gscb.org.uk

There are nine important parts to the Act, each of which makes substantial changes and new provisions to various areas of child welfare and family law.

PART 1: Adoption
PART 2: Family justice
PART 3: Children and young people with special educational needs (SEN) and disabilities, provisions put in place by the Act included the following:

			• A new Education, Health and Care (EHC) Plan based on a single assessment process will replace special education statements. EHC plans are documents that support children, young people and their families from birth to 25. • The commissioning and planning of services for children, young people and families is now run jointly by health services and local authorities as a result of the Act. • Extends the rights to a personal budget for the support to children, young people and families. • Local services available to children and families must be made available in a clear, easy to read manner. • Local authorities must involve families and children in discussions and decisions relating to their care and education and provide impartial advice, support and mediation services. PART 4: Childcare PART 5: Child welfare PART 6: The Children's Commissioner PARTS 7, 8, 9: Working Rights to Leave and Pay
	**National**	**Putting People First 2007**	The personalisation of social care and a positive change to involve individuals in the planning of their care.
Accessible Information Standard	**National**	**Equality Act 2010 & Accessible Information Standards (2018)**	Requires service providers to ensure information; service provision and the built environment are accessible for those who have a protected characteristic.

1.2 Key Challenges

Life Expectancy - increasing life expectancy means that people are living longer, but this may also mean with more complex needs. People living longer with frailty and impairment may require increasing levels of support to maintain their quality of life for as long as possible.

Funding - reductions in funding since 2010 and increasing demand for support requires commissioners to distribute resources differently. Our challenge is to work effectively, creatively and in an integrated way with our partner organisations in the NHS, other public bodies and the third (voluntary and community) sector.

To achieve this commissioners have asked the market to adopt an asset-based and enabling approach to enable greater choice and flexibility to support financially sustainable models of care and support. A key driver is for health and care provision to operate in a more person-led way to develop independent living options and links with mainstream health and social care support which will encourage economies of scale which maximise the resilience of people and help reduce health inequalities and support equity and equality.

Increased demand - increased demand - the number of people with Learning Disabilities is increasing. For Gloucestershire this means a projected 3.88% increase in the number of people with a learning disability (moderate to complex) between 2013 and 2020.

This includes a significant increase of 14.75% in the number of older people (over 65) with learning disabilities (moderate to severe).

It is anticipated over the next five years Local Authorities will continue to be under restraint as to available funds to invest in new services. The focus will be to demonstrate the cost effectiveness and quality of current services and to shift from 'endless services' to outcome based packages of care with clearly defined time limited outcomes expected of each provider. Commissioners will be intent on ensuring that funds expended are achieving specified outcomes and that efficiency strategies such as enablement, Telecare and new delivery models such as mobile support are being fully utilised to reduce the unit cost whilst maintaining or even improving quality outcomes.

Complexity of need changing -

Not enough support to help people with complex needs.

Currently 45% of our packages of support cost less than £500. 30% of our current packages are in the higher quartile; these packages a week are delivered to people with complex needs and represent a potential growing cost pressure to the authority.

Competent workforce

More consistent safeguarding knowledge is required across the workforce.

- Challenging Behaviour knowledge and skill levels are varied across provision.
- The need for appropriate communication training.
- Staff and management retention - 1/3 of services have had a new manager in the last year.
- Outcome-focused care planning must be more regularly used. Service Users need to be supported in a person-centred way with identified individual goals.

1.3 Scope & purpose of this report

To develop a common understanding of the needs of the population of people living with a learning disability or autism within Gloucestershire, identifying gaps, understanding opportunities for further development and identify shared priorities across the Health & Care System to support the Integrated Care System (ICS).

1.4 Defining Learning Disability

A person is identified as having a learning disability and being eligible to receive a service if **all** three of the following are present:

1. Significant impairment of intellectual functioning; and
2. Significant impairment of adaptive behaviour; and
3. Onset before adulthood

(The British Psychological Society, 2016)

Intellectual functioning: The person will have significant challenges in ***general*** mental ability which includes reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas, learning quickly and learning from experience. Just over 2.4% of people (determined by reference to a normal distribution with the general population) may be expected to have a general level of intellectual functioning commensurate with a diagnosis of a Learning Disability.

Adaptive behaviour: Concerns 'the collection of conceptual, social and practical skills that have been learned and are performed by people in their everyday lives'.

Examples may include:

- ***Conceptual skills:*** language, reading and writing; and money, time and number concepts:
- ***Social skills:*** interpersonal skills, social responsibility, self-esteem, gullibility, naivety (i.e. wariness), follows rules/obeys laws, avoids being victimised and social problem-solving.
- ***Practical skills:*** activities of daily living (personal care), occupational skills, use of money, safety, health care/transportation, schedules/routines and use of the telephone.

Relative to the general population a person with a Learning Disability has significant difficulties with such activities of daily life.

Onset before adulthood: Means there should be evidence of the presence of each of the other two criteria before the person attains the age of 18 years.

1.5 Defining Autism

There are many definitions of what Autistic Spectrum Conditions is, whom it affects and what impact it has.

People who have contributed to the Gloucestershire Autism Strategy (2018-2021) are working to the following definition which was chosen because it's simply put, endorsed by people with lived experience, is not excluding, doesn't describe people as "impaired" and is not medicalised.

> *"Autism is neither a mental illness nor a disease. It is neurodevelopmental in nature and reflects a difference in the wiring of the brain. This means you think, feel, perceive and react differently to the world around you and often have a different set of strengths and limitations. You learn that there are certain environments you feel more suited to than others. The challenge is finding the right settings that support the abilities".*

One Gloucestershire
Transforming Care, Transforming Communities

Learning Disability & Autism

#YourVoiceMatters

Learning Disability & Autism Strategic Needs Analysis

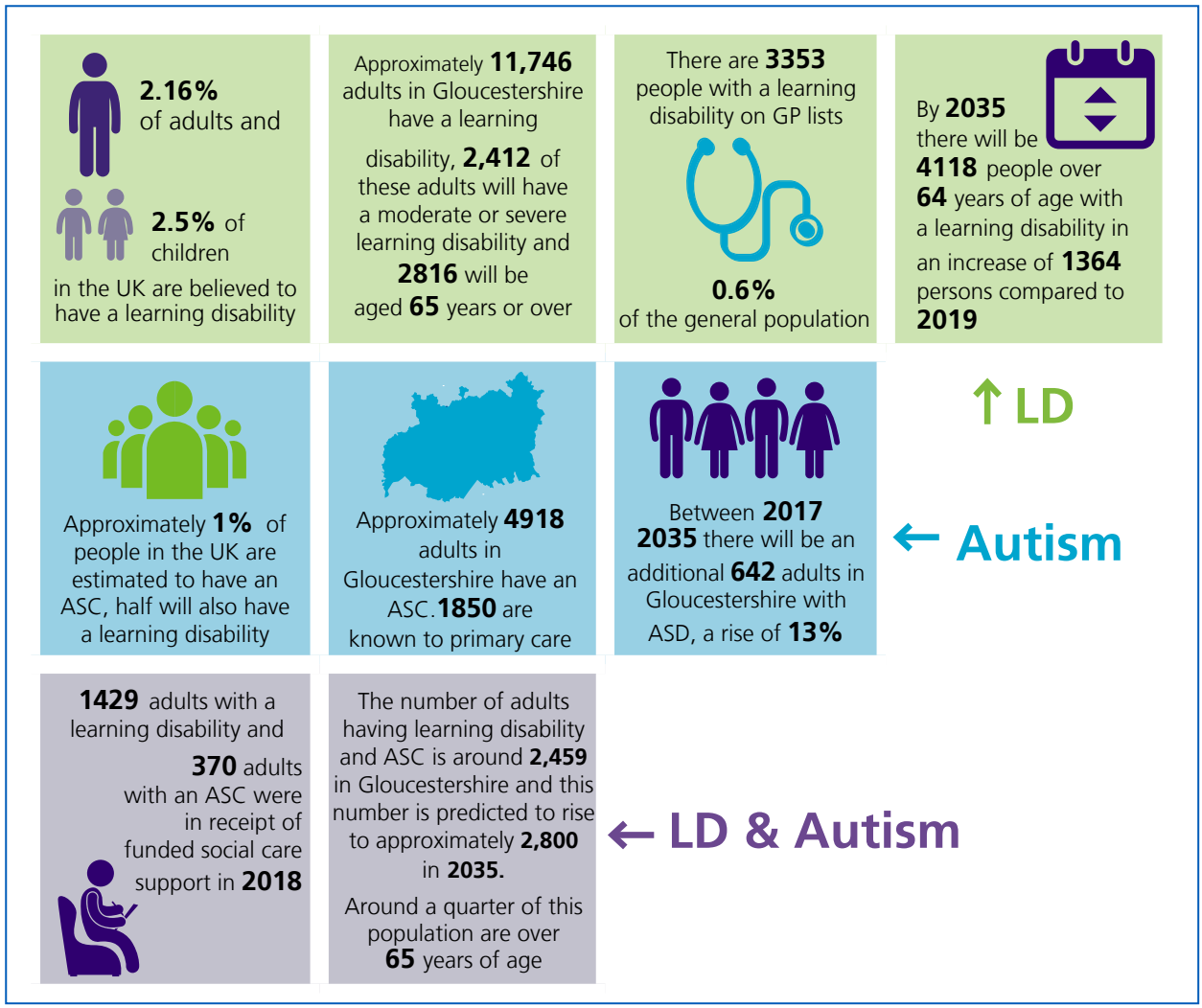
2018-2019

CHAPTER 2

Building a picture of needs in Gloucestershire

2. Building a picture of needs in Gloucestershire

2.1 Key Findings



2.2 Learning disabilities and health inequalities

The Improving Health and Lives Learning Disabilities Observatory (IHAL) found that people with learning disabilities have a shorter life expectancy and increased risk of early death when compared to the general population. 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.

> *"While the great majority (86%) of the illnesses that led to the deaths of people with learning disabilities were promptly recognised and reported to health professionals, for 29% there was significant difficulty or delay in diagnosis, further investigation or specialist referral, and for 30% there were problems with their treatment".*
>
> **Confidential inquiry into the premature deaths of people with a learning disability (CIPOLD) – University of Bristol - 2013**

The Improving Health and Lives Learning Disabilities Observatory (IHAL) identified the health inequalities from national data:

- People with learning disabilities have a shorter life expectancy and increased risk of early death when compared to the general population. 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.
- Health screening of adults with learning disabilities registered with GPs reveals high levels of unmet physical and mental health needs.
- 0.6% of patients with learning disability were registered as being in need of palliative care and support compared to 0.3% in patients without learning disabilities.
- Coronary heart disease is a leading cause of death amongst people with learning disabilities (14%-20%) with rates expected to increase due to increased longevity and lifestyle changes associated with community living. Almost half of all people with Down's syndrome are affected by congenital heart defects.
- 7.8% of GPs recorded people with a learning disability having a diagnosis of severe mental illness compared with 0.87% of people without a learning disability.
- 8.4% of people with a learning disability had a diagnosis of asthma compared with 6% of those without learning disability. Rates were higher for boys, peaking in the teenage years.
- Respiratory disease is possibly the leading cause of death for people with learning disabilities (46%-52%), with rates much higher than for the general population (15%-17%).

- The prevalence rate of epilepsy amongst people with learning disabilities has been reported as at least 20 times higher than for the general population, with seizures commonly being multiple and resistant to drug treatment.
- Among adults with learning disabilities, being non-mobile has been associated with a sevenfold increase in death and being partially mobile has been associated with a twofold increase of death when compared with being fully mobile. A population-based study in the Netherlands reported that people with learning disabilities are 14 times more likely to have muscular-skeletal impairments.
- More than 8% of adults known to learning disability services suffer from Dysphagia. 40% of those with learning disabilities and Dysphagia experience recurrent respiratory tract infections; other negative health consequences including asphyxia, aspiration dehydration and poor nutritional status.
  The prevalence of dementia is higher amongst older adults with learning disabilities compared to the general population (22% vs 6% aged 65+) and is associated with a range of potentially challenging behaviours and health problems. People with Down's syndrome are at particularly high risk of developing dementia, with the age of onset being 30-40 years, younger than that for the general population.

The following table (Table 1 - Likelihood of other conditions when compared with general population) uses data from NHS Digital on key health issues for people who are recorded by their GP as having a learning disability and comparative data about a control group who are not recorded by their GP as having a learning disability. In Gloucestershire this data represents 47% of those recorded as having a learning disability by their GP (as not all clinical systems could be analysed nationally) and highlights the increased prevalence of certain conditions in this population when compared to those without a learning disability.

When using the more complete local primary care dataset to compare prevalence between those with and without a learning disability the prevalence of these conditions remains higher, although not as significantly so, however this data is not age or sex adjusted so differences are likely due to this crude comparison[1].

Both data sources support the fact that those with a learning disability in Gloucestershire are much more likely to have a diagnosis of Epilepsy, mental health conditions (including schizophrenia, bipolar disorder and depression) and neurological conditions (e.g. Dementia and Parkinson's' disease). Both data sources also support the finding that those with a learning disability are more likely to experience some lifestyle related conditions such as Type 2 Diabetes.

[1]The local data is available upon request via SOLLIS.

Table 1 - Likelihood of other conditions when compared with general population

Illness	Comparison of prevalence of certain conditions (person with a learning disability compared to some-one in Gloucestershire without a learning disability (based on age/sex standardised prevalence ratio)
Epilepsy	More than 20 times higher
Mental health	9 times higher
Dementia	4 times higher
Hyperthyroidism	3 times higher
Heart failure	2 times higher
Stroke or Transient Ischaemic attack	2 times higher
Chronic Kidney Disease	2 times higher
Diabetes (Type 2)	2 times more likely
Cancer	Half as likely
Coronary Heart Disease	Half as likely

(Source: NHS Digital 2018 data for learning disability)

2.3 Learning Disabilities Annual Health Checks

Annual health checks are designed to promote the early detection and treatment of physical and mental health problems, which can lead to better health outcomes (Perry et al. 2010). Although the content and delivery of health checks have differed over time and across the country, a systematic review found that they were consistently effective in identifying previously undetected health conditions (Robertson et al. 2010).

Annual health checks will only be offered to people whose GP has registered them as having a learning disability. The number of people with a learning disability on GP registers is much smaller than the likely true number of people with a learning disability, although it should include those with the highest need.

Locally there are **3,353 people aged 14+** identified as having a learning disability by their GP (0.63% of the population of Gloucestershire). During 2017/18 2011 (60.0%) received a health check (Table 2 - Learning Disability Annual Health Check completed 2017-18). This varied by GP practice and primary care locality with the highest uptake of annual health checks completed within the Forest of Dean (72.4%) and the lowest in Cheltenham (46.6%).

Table 2 - Learning Disability Annual Health Check completed 2017-18

	No. on LD Register	No. received AHC	Locality %
Forest of Dean	601	435	72.4%
Stroud and Berkeley Vale	688	488	70.9%
Tewkesbury	224	146	65.2%
Gloucester City	1054	564	53.5%
North Cotswold	77	41	53.2%
South Cotswold	106	56	52.8%
Cheltenham	603	281	46.6%
Total	3353	2011	60.0%

Uptake of screening programmes for those recording as having a learning disability were significantly lower than that of the population without a learning disability and varied by locality;

Table 3 - Update of screening programmes for those with a Learning Disability

	% of People with LD age 25-64 who have had a smear in last 3 years	% of women age 50 - 69 with LD who received Breast screening in the last 3 years	% of people aged 60-69 with LD with a record of bowel cancer screening in the last 2 years	% of people with LD & Diabetes who have received a retinal screening in the last 15 months
Cheltenham	37.7%	35.5%	37.5%	52.2%
Forest	26.4%	49.4%	22.8%	71.4%
Gloucester	25.1%	34.5%	20.2%	57.5%
North	26.9%	66.7%	77.8%	66.7%
South	35.3%	57.1%	35.7%	56.3%
Stroud and Berkeley Vale	23.7%	55.9%	64.4%	56.9%
Tewkesbury	21.4%	44.4%	90.5%	71.4%
TOTAL	**27.4%**	**44.8%**	**39.5%**	**59.6%**

A number of potential barriers could have a negative impact on people with a learning disability from receiving healthcare. These are listed in Table 4 - Potential Barriers to equitable health.

Table 4 – Potential Barriers to equitable health

A lack of accessible transport links 	 Failure to recognise that a person with a learning disability or autism is unwell	Lack of joint working from different care providers 
Patients not being identified as having a learning disability 	 Failure to make a correct diagnosis	Not enough involvement allowed from carers 
Staff having little understanding about learning disability and or autism 	 Anxiety or a lack of confidence for people with a learning disability	Inadequate aftercare or follow-up care 

(Source: Heslop et al. 2013; Tuffrey-Wijnes et al. 2013; Allerton and Emerson 2012)

2.4 Autism and health

There are 1850 people with an Autism Spectrum Condition (ASC) in Gloucestershire who have been identified within primary care records. This represents 0.3% of the number of people registered with GPs in the county. Sources suggest that prevalence of autism is 1% of the general population (Brugha et al, 2012)[2] meaning the figure in Gloucestershire could be approximately three times lower than the national average. This may be a coding error or that people with ASC without a learning disability may not wish to be identified as such within their health records (or they are undiagnosed).

Table 5 - Audit of Autism records within Primary Care 2016-2017

Question	Audit Criteria	Glos CCG Q3 2013	Glos CCG Q3 2016	Variance
1	No. of people diagnosed with Autism (% based total practice population)	0.2% 1267/625830	0.3% 1850/633546	0.1% ↑
2	No. of people with suspected autism recorded (% based total practice population)	0.0% 50/625830	0.0% 73/633546	0.0% ↔
3	No. of people recorded with Autism with carer Status (% based on number of people with Autism)	21.8% 276/1267	25.7% 475/1850	3.9% ↑
4	No. of people recorded with Autism who has a carer and their carers details recorded (age or Ethnicity or other details) (% based on number of people with Autism who have a carer)	0.7% */274	2.9% 14/475	2.2% ↑
5	No. of people recorded with Autism with employment details recorded (% based on number of people with Autism)	12.0% 152/1267	14.3% 264/1850	2.3% ↑
6	No. of people recorded with Autism and living arrangements recorded (% based on number of people with Autism)	19.3% 244/1267	24.5% 453/1850	5.2% ↑
7	No. of people recorded with Autism also diagnosed with Learning Disabilities or Aspergers Syndrome with a Learning Disability health examination in last 15 months. (% based on number of people with Autism and also diagnosed with Learning Disabilities or Aspergers Syndrome)	53.0% 282/532	54.1% 379/701	1.1% ↑

[2]The NHS Information Centre, Community and Mental Health Team, Brugha, T. et al (2012). Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey. Leeds: NHS Information Centre for Health and Social Care.

2.5 Adults with a learning disability

2.5.1 Prevalence

By combining different information sources it is estimated that in the UK 2.16% of adults and 2.5% of children have a learning disability. However, the number of people with learning disabilities recorded in health and welfare systems is much lower with under 0.5% of the adult population recorded as having a learning disability on GP registers in 2015, although this is improving year on year (PHE, 2015 People with Learning Disabilities in England: Main Report[3].)

This pattern is observed in Gloucestershire where just over 0.5% of the population are documented as having a learning disability on GP registers (3352 persons in 2017/18). Typically people with a more moderate and severe learning disability are recorded as such on GP registers.

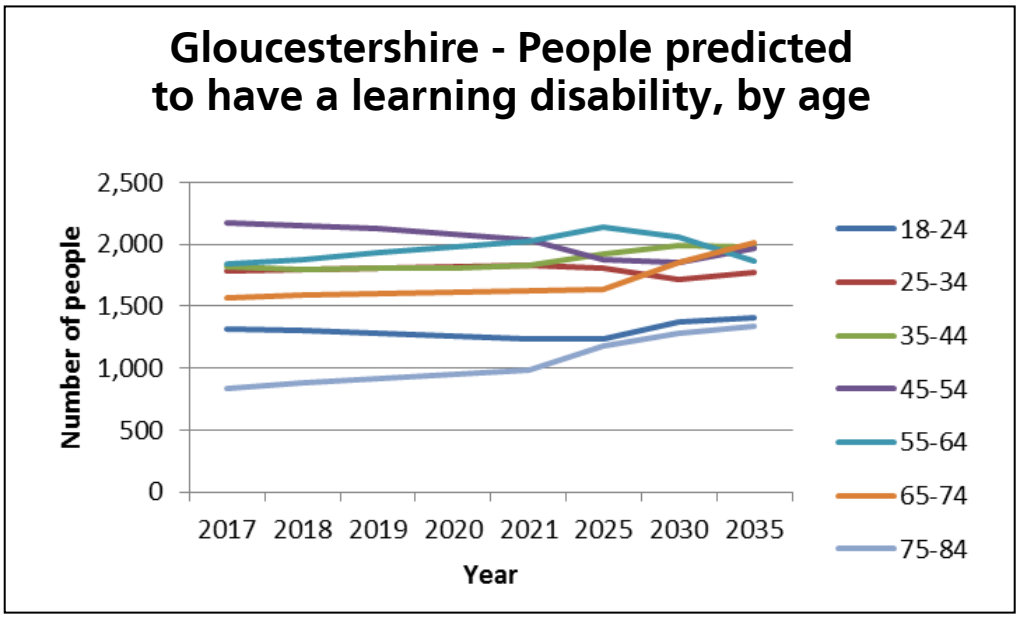
Therefore, using national estimates, there are thought to be 11,746 adults with some degree of learning disability living in Gloucestershire. Across the county around a quarter of the population are over 65 years of age.

2.5.2 Projection

The percentage of adults with a learning disability is predicted to rise by 12.3% between 2018 and 2035. The percentage is predicted to rise most steeply in the older age groups, rising by 119.3% for those aged 85 and over and 60.0% for those aged 75-84. By 2035 it is estimated that there will be 4,118 people aged 65 and over living in Gloucestershire[3], an increase of 1364 persons.

Within the 18-65 cohort it is predicted that the population will rise slightly by 0.8% over this period (equating to an additional 74 people). Further information is available in the appendices.

Chart 1 - People predicted to have a Learning Disability by age



SOURCE: PANSI

[3] (available from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf) [accessed on 01/08/2019]

2.5.3 Geographical distribution

Table 6 - Geographical distribution of adults with a learning disability by locality (aged 18-64)

District	Number of adults (aged 18-64) predicted to have an LD in 2018	% change in numbers of people with an LD between 2017 and 2035 (aged 18-64)
Gloucester	1938	+4.5%
Cheltenham	1799	+2.0%
Cotswold	1799	-3.5%
Stroud	1631	+0.1%
Tewkesbury	1241	+5.5%
Forest of Dean	1155	+7.0%

Table 7 - Geographical distribution of adults with a learning disability by locality (aged 65+)

District	Number of adults (aged 65+) predicted to have an LD in 2018	% change in numbers of people with an LD between 2017 and 2035 (aged 65+)
Gloucester	452	+58.7
Cheltenham	467	+47.2
Cotswold	469	+45.8
Stroud	560	+48.2
Tewkesbury	427	+52.9
Forest of Dean	445	+47.9

2.5.4 Prevalence of moderate and severe learning disabilities

People with moderate or severe learning disability are more likely to require social care services than those with mild conditions. Based on the report by the Institute for Health Research, PANSI and POPPI have estimated the number of adults with moderate or severe learning disability in Gloucestershire as shown in the following table. The percentage of people with moderate or severe learning disability is predicted to rise most steeply in the older age groups, rising by 56.3% for those aged 75-84 and 109.1% for those aged 85 and over between 2017 and 2035. By 2035 it is estimated that there will be 530 people aged 65 and over and 2,065 people aged 18-64 with a moderate or severe learning disability.

Table 8 - People predicted to have a moderated or severe learning disability and hence likely to be in receipt of services, by age

Age group	2017	2018	2019	2020	2021	2025	2030	2035	Change 2017 to 2035 (number)	Change 2017 to 2035 (%)
18-24	304	302	297	293	289	291	327	336	32	10.5%
25-34	382	385	389	391	392	387	369	380	-2	-0.5%
35-44	456	453	453	456	460	483	500	499	43	9.4%
45-54	486	483	476	467	455	423	422	450	-36	-7.4%
55-64	400	409	420	431	441	462	440	400	0	0.0%
18-64	2029	2032	2036	2036	2038	2,047	2,059	2,065	36	1.8%
65-74	253	256	257	260	262	266	300	325	72	28.5%
75-84	87	91	95	98	102	122	130	136	49	56.3%
85 and over	33	33	34	35	36	42	53	69	36	109.1%
65 and over	373	380	386	393	400	430	483	530	157	42.1%
18 and over	**2,403**	**2,412**	**2,422**	**2,430**	**2,438**	**2477**	**2542**	**2595**	**192**	**8.0%**

The increase occurred across age bands, with the 18-64 age group experiencing a rise of 22.3% compared with 9.6% among the over-65s in the same 5-year period. The rate of increase among the under-25s was particularly rapid, rising by nearly three-fold in the period.

In terms of service type, the increase between 2014 and 2018 has been solely for community care services (up 36.6%), while the numbers receiving funded residential or nursing care has reduced (down 12.8% and 37.5% respectively).[4]

2.5.5 Services in use

The number of adults in receipt of funded social care support whose primary support reason is learning disability has increased year-on-year from 1,186 people in 2014 to 1429 people in 2018, representing an increase of 20.5% over the 5-year period (around half those estimated to have a moderate or severe learning disability).

The following table demonstrates the proportions of Service Users documented on the Adult Social Care database (ERIC) according to their care banding.

[4] (Caveat: Primary support reason could change over time depending on the service user's main needs for services at the time. Autism is not recorded on ERIC as a primary support reason in its own right.)

Table 9 - Information from GCC - primary reason is Learning Disabilities - a snapshot[5]

			LD Band							
Type of funded support	**Number of people with Learning Disability**	**Gross Weekly Cost**	**A**	**AC**	**AM**	**B**	**C**	**D**	**D+**	**Null**
1. Residential	345	£469,362.08	35	26	30	153	88	9	1	3
2. Nursing	9	£9,600.11	1	0	2	4	1	0	0	1
3. Community - High Cost (£500+)	479	£624,103.42	27	46	39	177	159	20	3	8
4. Community - Medium Cost (£250 - £499)	262	£94,148.47	6	9	12	58	122	48	5	2
5. Community - Low Cost (£1 - £249)	306	£41,244.95	6	0	3	31	106	147	7	6
6. Low Level Support	24	£0.00	0	0	2	1	2	10	0	9
Unknown	38	£5.48	1	0	0	2	11	14	0	10
Total	**1463**	**£1,238,464.51**	**76**	**81**	**88**	**426**	**489**	**248**	**16**	**39**

SOURCE: GCC performance and analysis team

Band AC is "people with complex needs and behaviours that challenge"
Band AM is "people with profound and multiple disabilities"
Band A is "Learning Disabilities High Needs"
Band B is "Learning Disabilities"
Band C and D is "LD Low Needs"

[5]Notes
1. Figures could include health budget/money that will be reclaimed.
2. Data assumes that clients did not suspend service (there are occasions when some services could be suspended for hospital admission for example).
3. Figures do not relate to what Strategic Finance will present at year end, once savings and offsets have been applied.

2.6 Adults with Autistic Spectrum Conditions

2.6.1 Prevalence

Nationally it is estimated that around 1% of the population have an Autistic Spectrum Conditions (ASC). Within Gloucestershire's population of 620,000 this would provide an estimated figure of 4918. However, we do know that within Gloucestershire's Primary Care records this is recorded at 1850 people who have been coded with ASC. There is however, potentially a risk of mis-coding, people who have been undiagnosed or have not been coded as having ASC, therefore this number is an under-representation.

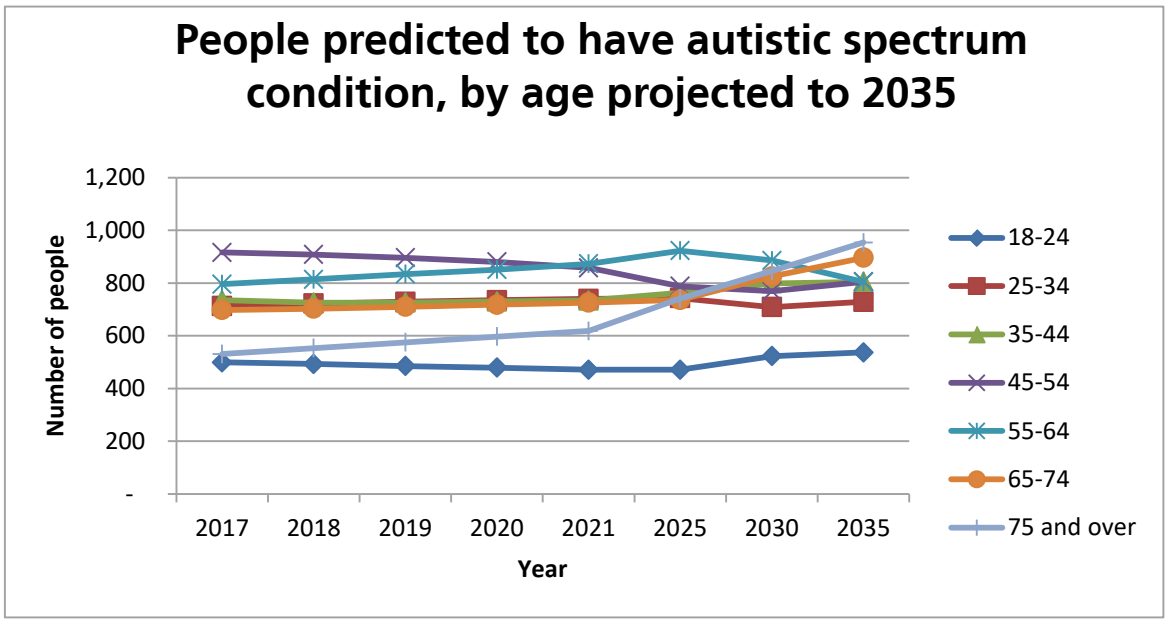
Autism is not a learning disability, but around half of people with autism may also have a learning disability, which will affect the level of support they need in their life. This suggests that the number of adults with a learning disability and an ASC is around 2459 in Gloucestershire, rising to 2765 in 2035. Across the county around a quarter of this population is over 65 years of age.

2.6.2 Projection

The percentage of adults with an ASC in Gloucestershire is projected to rise by 13.1% from 2017-2035, an increase of 642 people. The percentage is expected to rise most steeply in the older age groups, rising by 79.7% for those aged 75 and over; an increase of 423 people.

Within the age 18-65 cohort it is predicted that the population will rise slightly by 0.6% (equating to an additional 23 people). The greatest increase in this age group will be in the 18-24 year age group where the population is predicted to rise by 7.6%.

Chart 2 - Projections of ASC by Age



SOURCE: PANSI & POPPI

2.6.3 Geographical distribution

Table 10 - Number of people (18+) with ASC by locality

District	Number of people (aged 18+) with ASC
Gloucester	996
Cheltenham	944
Stroud	924
Tewkesbury	699
Cotswold	679
Forest of Dean	676
TOTAL	**4918**

2.6.4 Services in use

There are currently 370 adults diagnosed with ASC in receipt of a social care package of support with a total cost of £416,896.39 per week. This is an average of £1126.75 per person, per week[6].

There are currently 6 children diagnosed with ASC in receipt of CCG funded packages with a total cost of £84,947.58 per week. This is an average of £14,157.93 per person per week.

There are currently 19 children diagnosed with ASC in receipt of a residential social care package of support with a total cost of £50,743.58 per week. This is an average of £2,670.71 per person per week.

There are 1850 people who have been identified with ASC within primary care records who are receiving additional support from their GP.

Think Autism identifies the need for early intervention and we have seen an increase in the level of support required for people with ASC. The Gloucestershire Mental Health and Wellbeing Service supports adults with ASC as required, however they have only supported 54 people with ASC in 2017-2018, as a result of this a post diagnostic advice and support service has been commissioned in 2019.

The local draft Autism Strategy clearly states that there is insufficient post diagnostic support leading to an increase in crisis intervention rather than Tier 1 and Tier 2 conversations. Almost without exception families, professionals and organisational representatives stress that while a diagnosis can be helpful as a gateway to some statutory services; it primarily identifies a "problem" and not what to do about it.

[6] Due to data recording we are currently unable to get a comparator for this.

People with Autism and their families say that getting support after a diagnosis that grows understanding and knowledge of how to manage living with a diagnosis makes a fundamental difference to the quality of people's lives. People with ASCs and their families tell us that just as the condition is life long, so too is the need for support. The amount and type of support needed varies, depending on age and circumstances. The Autism Partnership Board is leading on an Autism Strategy in Gloucestershire to identify and seek solutions to provide the level of support people with ASC require.

We know that getting a diagnosis can be difficult for people with ASCs and their families. Specifically, children and young people's diagnostic pathway is reported to be convoluted and difficult to navigate for families. Often, neither knows much about what Autism is and it's not uncommon to meet people who have been diagnosed for some time who don't understand their diagnosis, or the implications of living with ASCs. Having a diagnosis is not useful if you don't know what it means or how to help yourself or a family member who has been diagnosed.

Adequate post diagnostic support was identified as the highest priority in Gloucestershire because it affects everyone in a range of ways, including their mental health, their independence and way of life. It's not only people with ASCs who need support post diagnosis. Parents, siblings and close friends want to provide support, but often don't know what to do or how to do it. The impact of a diagnosis on families can be significant.

There's a risk that when we talk about "post diagnostic support" we end up thinking about all of the services and supports that are and could be available to people with ASCs and their families. Unless children are supported within specialist services, there is very little post-diagnostic support for them or their families. The Advisory Teaching Service used to run a post-diagnostic course known as the Early Bird Course, however this has currently ceased.

The current caseload of the Adult Autism Diagnostic Service provided by 2Gether NHS Foundation Trust (as at Sept 2019) is 224 people with 203 people waiting for assessment and 23 in the triage phase. The approximate waiting time for assessment is 14 months. The National NICE Quality standards for an assessment being started is 3 months.

2.7 Children and Young People with Learning disability and/or Autism

2.7.1 Prevalence

We know that the number of people with ASCs is increasing but this may be related to more information available about the condition and better diagnosis.

The ASD prevalence in children by age is detailed in Table 11.

Table 11 - ASD prevalence in England from Mental Health of Children and Young People in England, 2017 [PAS] Official statistics. Publication date: 22 Nov 2018

This equates to the following figures for Gloucestershire.

	5 to 10 year olds	11 to 16 year olds	17 to 19 year olds	All
	%	%	%	%
Pervasive Developmental Disorder (PDD)/Autism Spectrum Disorder (ASD)	1.5	1.2	0.5	1.2
Pervasive Developmental Disorder (PDD)/Autism Spectrum Disorder (ASD) Boys	2.5	1.8	1.0	1.9
Pervasive Developmental Disorder (PDD)/Autism Spectrum Disorder (ASD) Girls	0.4	0.7	-	0.4

Table 12 - ASC Prevalence and Actual Figures for Gloucestershire

The expected prevalence of children and young people is highlighted in the tables above, however without a full dataset across agencies it is difficult to provide the actual prevalence figures, to gauge if Gloucestershire is in line with expected prevalence.

Age	0 to 4	5 to 10	11 to 16	17 to 18	0 to 18
Number of children	34766	44019	40886	14875	134546
Expected number with ASD	417.2	660.3	490.6	74.4	1642.5
Expected number using average prevalence	417.2	528.2	490.6	178.5	1614.6

2.7.2 Projections

The population of children and young people (those aged 0-19) is projected to rise by 11.0% over the twenty-five year period which is in line with the trend for England and Wales (Gloucestershire Children and Families Needs Assessment, 2018). By 2024, there will be a population of 148,200 children and young people in Gloucestershire.

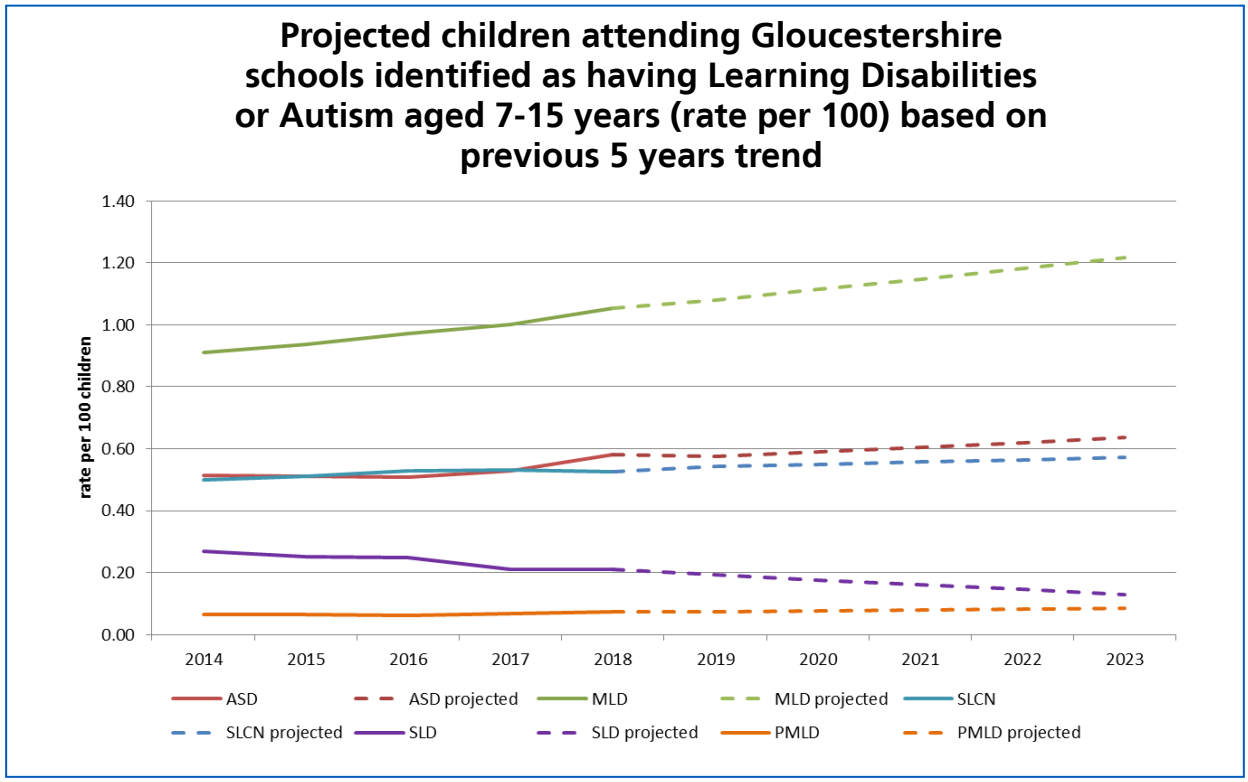
According to projections the number of children with LD and Autism will continue to increase over the next few years as shown in Table 13.

Table 13 - Projections of those children in schools identified with learning disability and autism between ages 7 – 15

Projected children in Gloucestershire schools with Learning Disabilities & Autism aged 7-15 years										
	Actual numbers from SEN2 census aged 7-15 years					Projected numbers aged 7-15 years				
	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023
Actual total LD & ASD	1279	1295	1332	1362	1451					
Previous 5 year rate trend						1503	1557	1609	1654	1701
Average rate previous 5 years - 2.33						1421	1446	1468	1483	1500
2018 rate - 2.45						1494	1521	1544	1559	1577
UK rate 2.91						1777	1809	1836	1855	1876

Chart 3 below shows the rate per 100 children of each primary need with projections of how these may increase if the previous 5 year trend continues.

Chart 3 – Projected children attending Gloucestershire schools identified as having Learning Disabilities of Autism aged 7-15 years (rate per 100) – based on previous 5 years trend



2.7.3 Current Numbers in Gloucestershire

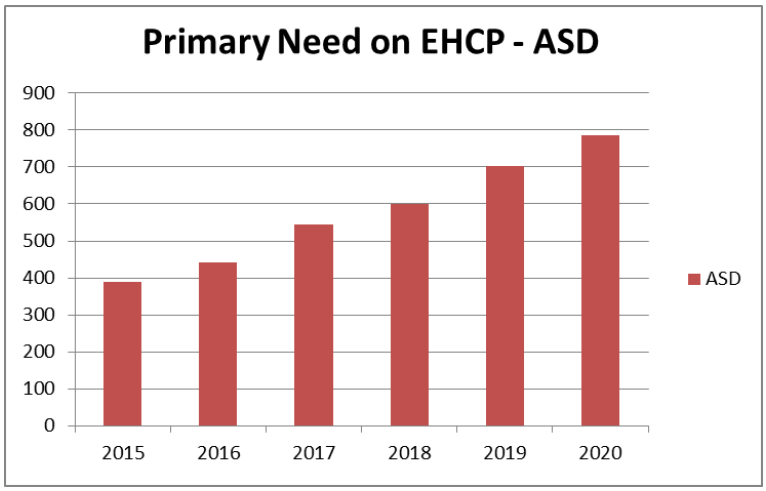
The Learning Disabilities actual school census data for Gloucestershire shows that the number of children with an LD or ASC as a proportion of the population of children aged 7-15 has risen by 0.19% between 1/1/2014 and 1/1/2018. There does not appear to be any significant increases in the proportion of children in any of the categories of learning disability compared to the total population of 7-15 year olds between 2014 and 2018.

Table 14 - Number of children age 7-15 with a learning disability or ASC by year

Learning Disabilities actual					
	01/01/2014	01/01/2015	01/01/16	01/01/17	01/01/18
ASD	291	291	292	307	345
MLD	571	533	558	582	625
SLCN	283	291	303	310	312
SLD	152	143	143	123	125
PMLD	36	37	36	40	44
Total LD & ASD	1279	1295	1332	1362	1451
Sch Census 7-15	**56703**	**56925**	**57486**	**58208**	**59312**

The Education Health and Care Plan data below shows that Autism as the primary need in EHCP has increased year on year.

Chart 4 – Number of children with ASC as a primary need on their Education Health and Care Plan.



2.7.4 Education, Health and Care Plans

A child or young person has Special Educational Need if they have a learning difficulty or disability which calls for special educational provision to be made for them. Children with Special Educational Needs will be supported by a group of professionals within the Early Years setting and if further help or support is deemed necessary the lead practitioner may apply for an Education, Health & Care Plan (EHCP) to be put in place.

There are currently 3867 children with open EHCPs in Gloucestershire. The table below shows the number of children and their education provision (This is all residents of Gloucestershire, including those that attend schools out of county but not children who attend Gloucestershire schools but are ordinary residents of another authority).

Table 15 - Current Number of CYP with an EHCP by provision.

Provision type	Current number of C&YP with an EHCP	Percentage
EY Settings	25	0.6%
Maintained Mainstream Schools/Academies	1,680	43.4%
Maintained Special Schools/Academies	1,171	30.3%
NMS / Independent Schools	207	5.4%
Alternative Provision Schools	39	1.0%
Elective Home Education	42	1.1%
General FE / Training Providers	438	11.3%
Special Post 16 Institutions (SPIs)	55	1.4%
Social Care Setting	2	0.1%
Awaiting Provision / No registered base	208	5.4%
Total	**3,867**	

Cost of EHCPs

The cost of EHCPs in 2018 for children with LD and ASC is detailed below and totals £6.4M. Children with a PMLD receive the bulk of their funding through other sources.

Table 16 - EHCPs in 2018 for children with a learning disability and ASC

EHCP projected annual support costs 2018/19 - Children from 2018 Census in Gloucestershire primary and secondary schools			
	7-15 yr	16+ yr	Grand Total
ASD	£ 1,296,066	£ 71,442	£ 1,367,508
MLD	£ 3,196,870	£ 35,522	£ 3,232,392
PMLD	£ 6,150	-	£ 6,150
SLCN	£ 1,601,252	£ 21,047	£ 1,622,299
SLD	£ 214,119	-	£ 214,119
Grand Total	**£ 6,314,457**	**£ 128,011**	**£ 6,442,468**

2.7.5 Geographical distribution

Of the 1451 children aged 7-15 with an EHCP where the primary need was LD or ASC the highest number was found in Gloucester as shown in the map below.

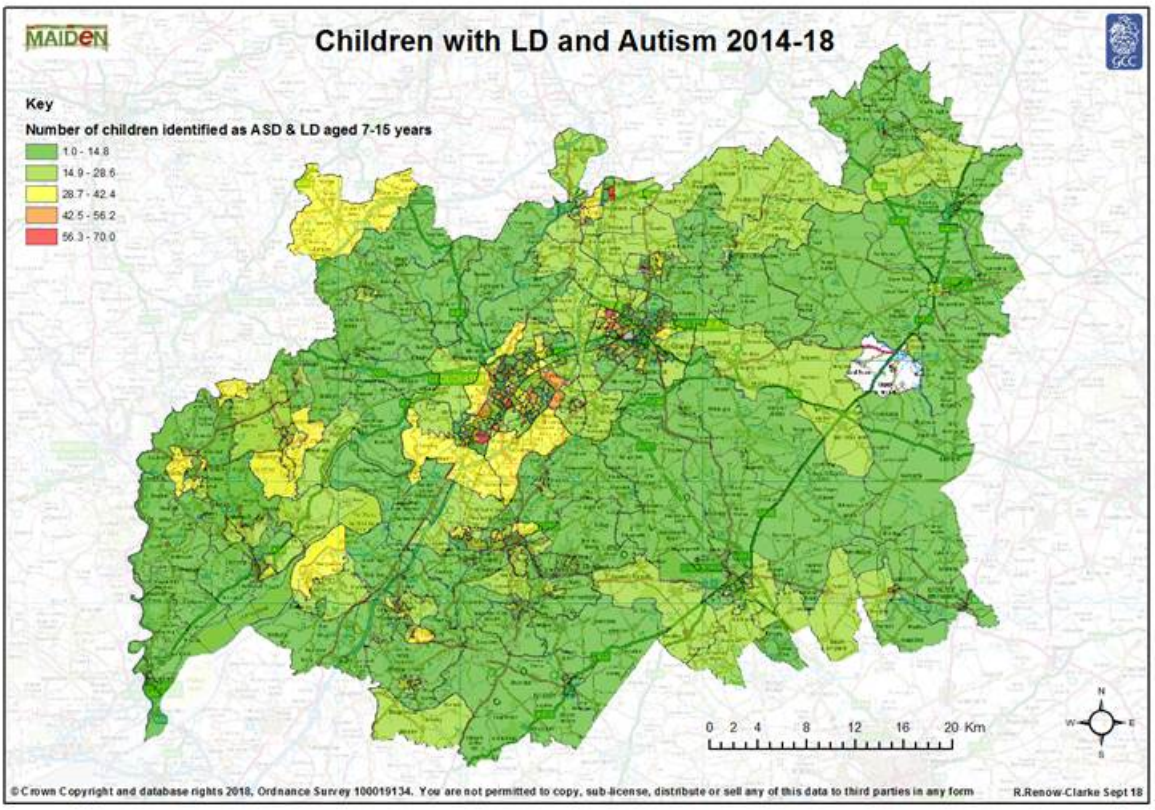


Figure 1 - Geographical map of children with LD and ASC in Gloucestershire

However the districts with the highest rates (per 100 children with primary need recorded as LD or ASC in 2018) of children with an EHCP where the primary need was LD or ASC were Cheltenham and Forest of Dean. The table below shows the rate of children with EHCPs by each LD or autism primary need across the county.

Table 17 - Number of children aged 7-15 where the primary need was LD or ASC

Number of children with learning disability recorded - 2008 School SEN Census							
	Cheltenham	Cotswold	Forest of Dean	Gloucester	Stroud	Tewkesbury	Gloucestershire
All LD/ASD	274	121	184	400	241	221	1451
All EHCP	382	192	296	556	347	298	2093

Table 18 - Rate per 100 children with primary need recorded in 2018 by geographical location

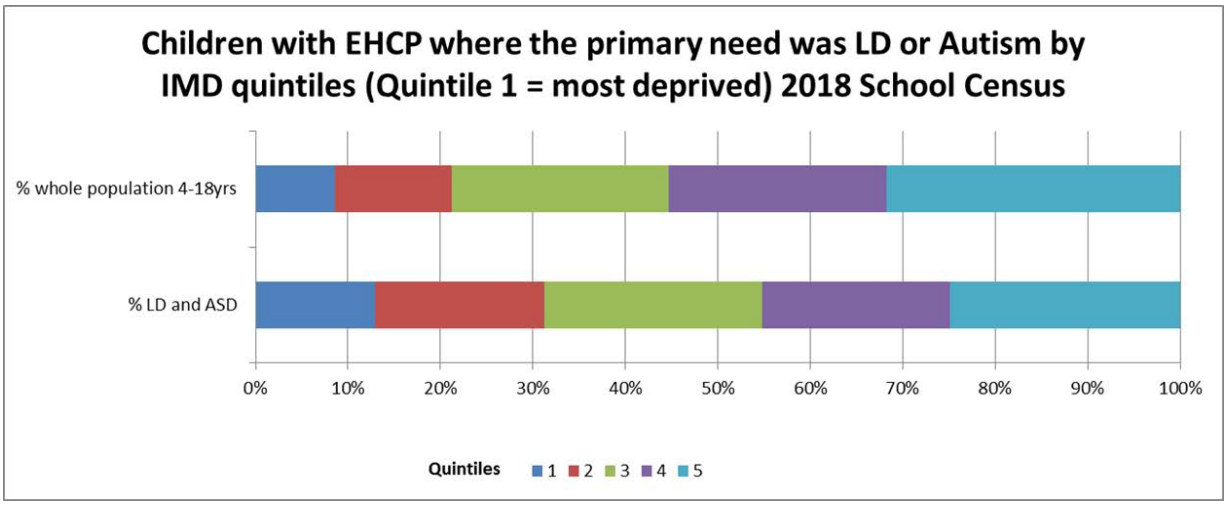
Rate per 100 children with primary need recorded as ASD or LD - 2018							
Need	Cheltenham	Cotswold	Forest of Dean	Gloucester	Stroud	Tewkesbury	Gloucestershire
ASD	0.74	0.35	0.54	0.64	0.56	0.58	0.58
MLD	1.46	0.67	1.03	1.18	0.88	1.01	1.05
PMLD	0.07	0.02	0.07	0.10	0.07	0.08	0.07
SLD	0.14	0.18	0.26	0.32	0.17	0.14	0.21
SLCN	0.15	0.20	0.63	0.63	0.47	0.61	0.53
All LD/ASD	2.93	1.43	2.54	2.87	2.16	2.42	2.45
All SEN	**4.08**	**2.26**	**4.08**	**3.99**	**3.11**	**3.27**	**3.53**

LD and Autism and Deprivation

Children aged 4-18 years in Gloucestershire with learning disabilities or ASC are over represented in more deprived communities than the general school age population, as shown in Chart 5.

ASC is the only primary condition that follows whole population distribution, MLD is the most over represented in more deprived quintiles with 37% living in Quintiles 1 and 2 compared to 21% in the general school age population.

Chart 5 - Children with EHCP where the primary need was LD or Autism by IMD quintiles (Quintile 1 = most deprived) 2018 School Census



2.7.6 Identification and Diagnosis

Early identification and intervention are vital to enable children and young people to reach their full potential.

Children with a congenital condition that will affect their development that is detected either during ante-natal tests, at birth or shortly after birth will often receive a learning disability diagnosis straight away. For other children the identification and diagnosis of a learning disability will be more complicated and may not happen until the child is older and in an educational setting.

The Health Visitor will undertake a 1 year and a 2/2.5 year developmental check on all children which will compare them to expected milestones for their age, many difficulties will be identified at this stage. Some developmental delays will resolve as the child grows up but other conditions will be lifelong.

A significantly higher proportion of children with an EHCP for MLD had summer birthdays in EYFS & KS1 - suggesting these children may be over diagnosed. This may be indicating children in the summer birth cohort are more likely to exhibit 'developmental delay' that could be misdiagnosed as a learning disability in the early years but however this would have to be investigated further.

Table 19 - Summer births cohort compared to Autumn/Spring cohort of 5 of children with MLD

Summer birth cohort compared to Autumn & Spring cohort % of children MLD		
	p-value	
	EHCP	SEN only
EYFS & KSI	0.019	0.626
KS2	0.063	0.327
KS3	0.379	0.159
KS4	0.095	0.389

Autism

There are NICE guidelines for the diagnosis of autism that need to be followed. The NICE Guidance Autism Quality Standard (Q51) requires people with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral. Currently, the pathway for diagnosis for children and young people is not fully NICE compliant, however improvements are in progress to address this. Guidelines state that the assessment team should comprise speech and language therapy (SLT), Clinical/ Educational Psychology and Psychiatrist/Paediatrician, with the families supported through the process by a care coordinator.

The process for diagnosing autism is often complex and requires input from a number of different professionals. This can mean a period of time where a child needs to be monitored and assessed which can be frustrating for families but will ensure the diagnosis is valid.

There is currently a pre-school social communication pathway in Gloucestershire with multi-agency professionals working together to diagnose children with autism. Referrals to this pathway are increasing, this could be due to the rise in awareness of autism, as well as increasing prevalence within the population.

Out of the 207 parents and carers asked in the Children's ASD survey 74 of them stated that it took over 2 years for their child to receive a diagnosis of autism, with a further 60 still awaiting diagnosis.

Chart 6 - Parent feedback on waiting times for ASC Diagnosis

The current wait for the preschool clinic assessments for children with suspected ASD in Cheltenham is 5 months, with 15 children waiting. The current wait for the preschool clinic assessments in Gloucester is 22 children which equates to a 7 month wait (Summer 2019 figures). These waits are building towards 9 months in both areas (as at Jan 2020) despite working hard with referrers to ensure referrals are appropriate. Once a clinic assessment has been completed, there is a further wait for final formulation and feedback, so the waiting time can be approximately 1 year in total.

For the 5-11 age group, referrals are made to the paediatrician service and referrals are only accepted if there is a report from the school / Educational Psychologist / Advisory Specialist Teacher service. This means that the waiting list is managed well and those who have obvious signs of autism with all the necessary reports can obtain a diagnosis fairly easily.

The waiting time to the 5-11 years service is within the 18 week timescale. The service conducted an audit at the request of commissioners in July 2019. In a 2 month period, 21 referrals for ASD were received.

Total waiting times are hidden however, as referrals are not accepted until specialist teacher reports and educational psychology reports have been completed. This causes a challenge for those who are home educated or where school does not observe any issues within school. In addition, there is a lack of a multi-disciplinary team to support paediatricians, although improvements through redesign are in progress. For 11-18 year olds, a clinic operates a specialist assessment and diagnosis service for neurodevelopmental disorders (ADHD, ASD alongside mental health co-morbidities) for children and young people. There is a waiting list for Neuro clinic, which is around 12 months.

2.7.7 Services in use

For children and young people with an Education, Health and Care plan, the best outcomes are not purely achieved by the plan itself, but by people successfully working together through a Team Around the Child or Team Around the Family approach. This approach allows all those working with a child, young person or family to act as a team; sharing knowledge and experience, finding creative solutions to meet needs, reviewing progress and ensuring clear and consistent communication with families.

Education

The 2018 Special Educational Needs (SEN) Census outlined that 13,485 children were receiving some kind of SEN support in schools, the highest proportion, 31% of these had Moderate Learning Disability (MLD) as the reason given for this. 19% of those receiving support were receiving EHCP support, 81% were receiving other SEN support. Children with Moderate learning disabilities, Social, emotional and mental health, Speech, Language and communication needs or Specific Learning Difficulty (Dyslexia) were much less likely to have an EHCP than other children with Special Educational Needs. This is usually because many needs can be met within the graduated pathway.

Table 20 - Number of children with a disability being supported in a mainstream school - ordered by disability

Type of support	ASD	HI	MLD	MSI	NSA	OTH	PD	PMLD	SEMH	SLCN	SLD	SPLD	VI	Grand Total
Grand Total	**635**	**176**	**4240**	**19**	**363**	**740**	**305**	**149**	**2091**	**2105**	**560**	**1988**	**114**	**13485**
Percentage of total EHCP	3.4	0.2	2.8	0.1	0.0	0.7	0.9	1.1	2.8	2.3	3.9	0.7	0.1	19.0
Percentage of total SEN support	1.3	1.1	28.7	0.1	2.7	4.8	1.3	0.0	12.7	13.3	0.3	14.0	0.7	81.0

The majority of children and young people with additional needs are supported in mainstream settings, learning alongside their peers in their local community. However, Gloucestershire has a number of special schools/settings to meet the needs of those children and young people whose SEND needs require a more specialised environment (see Table 21). We know that children and young people have a range of needs which do not always fit neatly into either mainstream or specialist education settings so creating a range of provision which reflects the whole spectrum of need is a focus for development. This development will look to ensure the right school places and provision available at the right time for pupils.

Table 21 Number children with LD and/or ASC in Gloucestershire attending LA special schools.

School Name	2018 NOR
Alderman Knight School	137
Battledown Centre for Children and Families	36
Belmont School	109
Bettridge School	145
Greenfield Academy	7
Heart of the Forest Community Special School	92
Paternoster School	51
Peak Academy	57
The Milestone School	314
The Ridge Academy	46
The Shrubberies School	120
LA Special Schools Total	**1114**

School exclusions

Gloucestershire has a higher rate of children excluded from school than the national average – in the 2017/18 academic year 0.14% of the school population in Gloucestershire (123 children) was permanently excluded from school compared to 0.10% nationally. 49% of these were children with SEND which is a slight decrease from previous year DfE: Permanent and fixed period exclusions in England).

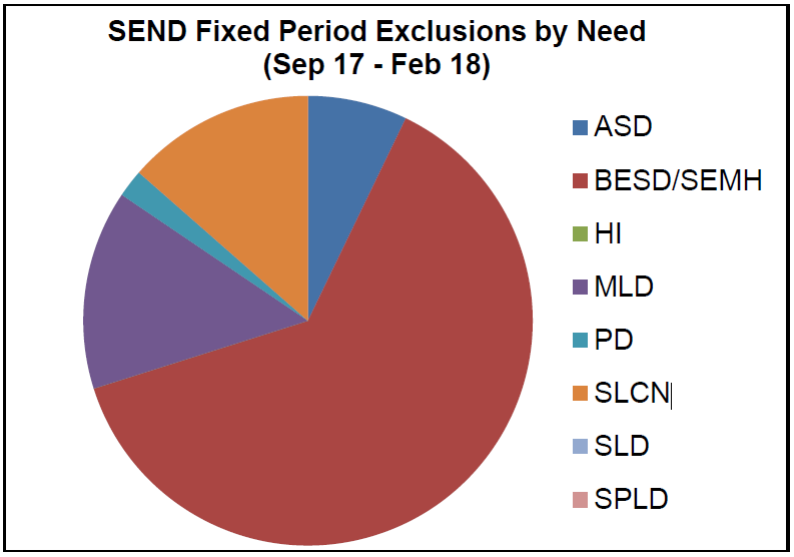
(https://www.gov.uk/government/collections/statistics-exclusions).

Of particular concern is the rise in children of primary school age who are being 'held' in primary schools and the number of children and young people who are removed from school by their families to home educate as they feel a school cannot provide the support they need.

The most common reason given for exclusion was 'Persistent disruptive behaviour' (PDB). Where a child had LD or ASC a higher proportion of children were excluded for 'Physical assault/violence against an adult' (20% vs. 4%), 'Racial abuse' (6.7% vs. 0%), 'Theft' (6.7% vs. 2%), 'Verbal abuse/threatening behaviour to adult' (13.3% vs.8%) than those with no SEN. However children with LD or ASC were less likely to be excluded for 'Drug and alcohol abuse', 'Bullying', and 'Verbal abuse/threatening behaviour against a pupil'.

Chart 7 below shows the main conditions relating to fixed term exclusions in 2017-18 were social, emotional and mental health, moderate learning disability and speech and language and communication, Autistic spectrum condition was the fourth condition. Undiagnosed ASD may well be a feature of the other conditions labelled against these fixed term exclusions. Parent carers report that exclusions and decisions to home educate children are factors around some cases where there is suspected autism.

Chart 7 shows of all the exclusions in the academic year, only 10.6% were where the identified need was LD or ASC.



Social Care

The council's social care services and its partners help children and young people achieve the best outcomes possible. This is delivered through the Graduated Pathway of Early Help and Support and through the Early Help Offer within the disabled children and young people's service when a greater level of support may be required.

The number of children in care has increased significantly from 460 in March 2012 to 746 in February 2020. This follows a national trend of an overall increase in the rise of children in care across the country with a proportionately increased number having additional needs. The number of children with complex needs has been increasing year on year (a report commissioned by the Council for Disabled Children & True Colours Trust reports over a 50% increase since 2004) and the needs they have are becoming more complex. Reasons for this include:

- Increased survival rates at birth of babies with complex needs/born prematurely;
- Increased Life-expectancy for life-limiting conditions;
- Increased survival of children post key trauma or illness;

These groups of children have significant health and care needs requiring individualised packages of care through the continuing care framework and joint funding with social care.

The disabled children and young people's service offers Early Help assessments and support as well as statutory assessments and support through the 1989 Children's Act, Chronically Sick and Disabled Persons Act 1970 and the Care Act 2014. Support can be provided through information, advice and guidance, signposting to other services such as Enablement, Carers Assessments and support, Employment at transition age and/or personal budgets - all working within the principles of the Building Better Lives policy.

The aim of the disabled children and young people's service is to provide support through childhood and also preparation for adulthood through information, advice and guidance which promotes an effective transition for young people to minimise the frequency of "telling the story" This includes providing a joined up service and to ensure support remains in place from Children's Services until the Care Act assessment can be concluded and decisions made in relation to provision of support to meet eligible assessed needs. Social care provide support and services to children who have statutory plans and make every effort to join up these processes and work in partnership with the Independent Reviewing Officers (IRO's), Virtual School and Care Leaving Services to enable needs to be met.

The disabled children and young people's service will have the key role in linking with SEN colleagues and partners within health to support a young person prepare for adulthood and support through transition. Some young people may receive support from Social Care teams outside of this team and the disabled children and young people's service is available to provide advice and guidance on transition.

There are approximately 480 children known to the Disabled Children and Young Person's Service (DCYPS). There are 91 children with disabilities open to the Safeguarding Team as Children in Need, Children and Care and children on a CP plan.

There is an increased number children with disabilities in care compared with December 20, this is in line with increased numbers of children in care. There were 66 children with disabilities in care in December 20 which has risen to 77 children in care in December 20.

Health

NHS Gloucestershire Clinical Commissioning Group CCG is responsible for commissioning local NHS services to meet the needs of local people. Currently the provider organisations commissioned to provide these services are Gloucestershire Health and Care NHS Foundation Trust (GHC) and Gloucestershire Hospitals NHS Foundation Trust (GHT). There are contracts and service specifications between the CCG and the provider organisations to ensure the services deliver in line with the expected outcomes from each service specification. The CCG routinely monitors the delivery of each service against their specification to ensure quality of delivery and value for money. Whilst providing services for the whole population, including children, the provider organisations work jointly with education and social care to ensure a holistic approach to meeting any additional needs.

In response to the new SEND Code of Practice (2015), which emerged from the Children and Families Act 2014, the CCG has developed a model for the delivery of the Health requirements. This model consists of 4 SEND representatives, one from each NHS Trust and one from the CCG, acting as the Designated Medical Officer (DMO) or Designated Clinical Officer (DCO). The benefit of this is that there is one direct link to each of the health service areas which makes development and working together far more effective and DCOs/DMOs support clinicians across the services to engage with the EHCP process and contribute to assessments and plans.

GHC provides community health services including health visiting, school nursing, the children in care nursing service, children's community nursing team and the children's therapy services. The Speech and Language Therapy, Occupational Therapy and Physiotherapy are part of the therapy services for GCS. Therapists are involved if a child has been referred into the service and assessed to require ongoing support to address the highlighted health issue identified. Therapists will provide advice, training and support to teaching and support staff or other professionals as appropriate, to facilitate children and young people accessing their education provision. Some of the special education needs schools have therapy services based on site and are able to see children in the education setting.

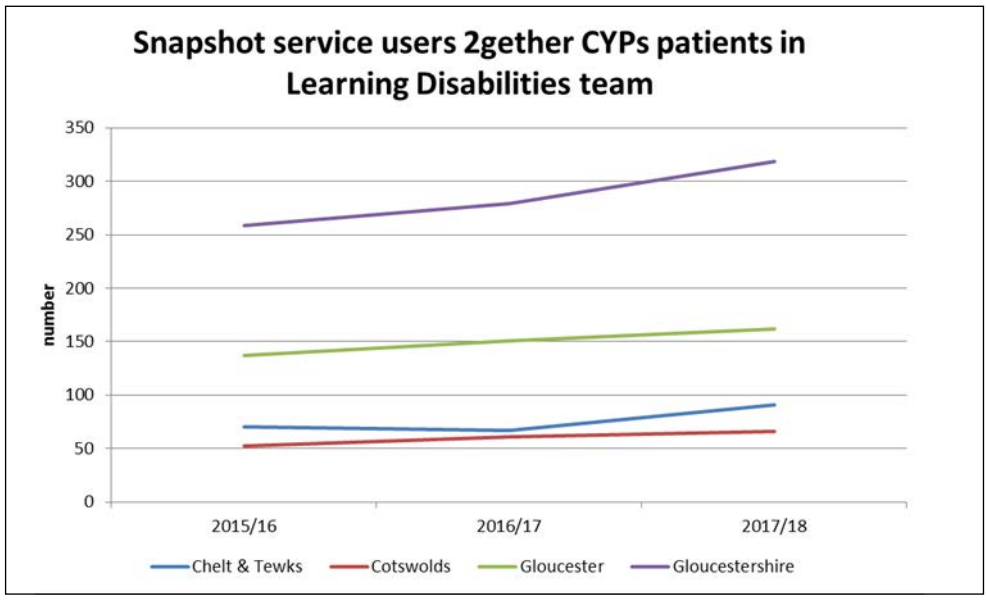
The Health Visiting and School Nursing services are part of the GHC Public Health Nursing service. These services are universal services available to all children and families in Gloucestershire. There are screening programmes at specific ages in both services to help identify if children may have additional health needs that may impact on their educational needs. There are specific members of the health visiting team whose role is to work with children and families who are known to have additional needs. There is also a special school nursing team who works closely with the special educational needs schools to ensure that health needs are being met to ensure that the childrens education is not negatively impacted.

Children with learning disabilities and/or autism may also be under the care of a paediatrician if they have additional health needs.

Children and Young People's Learning Disabilities Team (CAMHS LD)

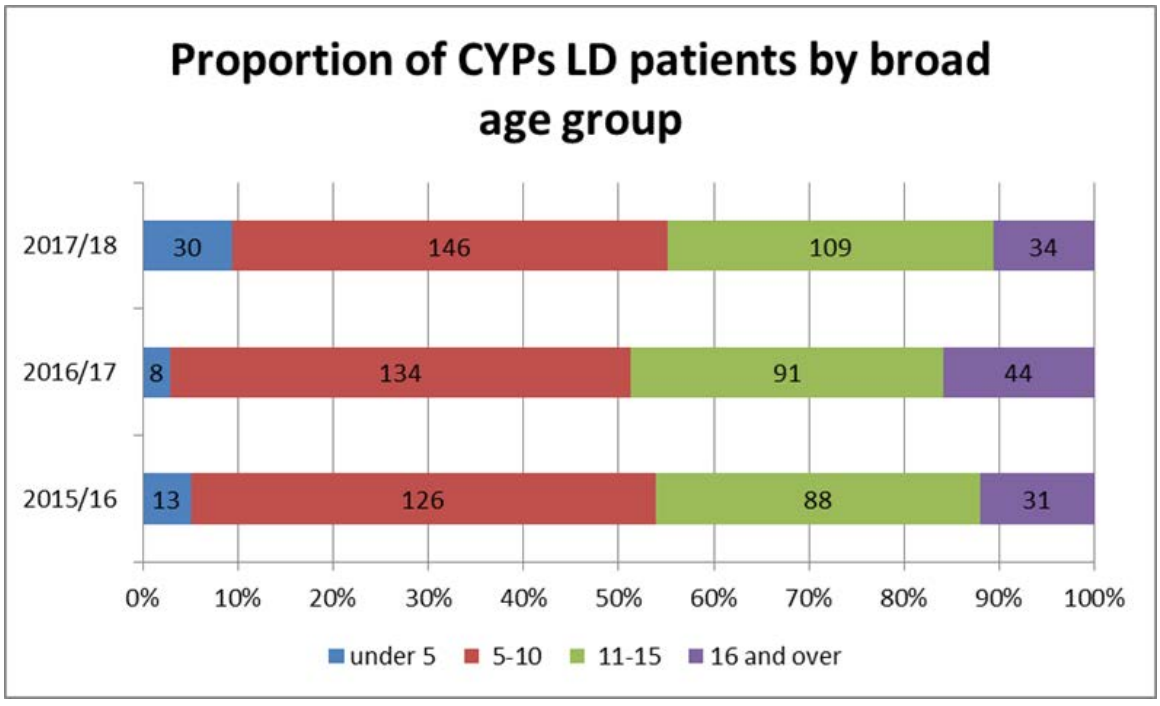
Gloucestershire Health and Care NHS Foundation Trust CAMHS LD team works with children and young people with moderate, severe and profound learning disabilities. The child will have challenging behaviour or may be having a specific issue, leading to distress and/or functional impairment that cannot be resolved through universal intervention. There are currently 208 children on the active caseload for CAMHS LD Service. There has been a slight increase in the number of service users using the CAMHS LD team in the last 3 years, as seen below.

Chart 8 - Snapshot of 2G LD CYPS team utilisation past 3 years



The CYPS LD team work with children and young people of all ages as demonstrated in the breakdown in Chart 9 below.

Chart 9 - Proportion of LD CYPS patients by age group



A significant proportion of the children and young people referred to CYPS LD are seen within 4-8 weeks as demonstrated in chart 9. This initial appointment assesses the child or young person and establishes what outcomes the family would like to achieve with the support of CYPS LD.

Table 22 – Time to first contact (unadjusted) (March 2015 – March 2019)

Team	Wait Time	2017/18	2018/19	2019/20	Grand Total
CYPS - LD Service	0-4 weeks	61	64	40	**165**
	4-8 weeks	13	26	9	**48**
	8-12 weeks	10	18	1	**29**
	12-16 weeks	4	13		**17**
	16-20 weeks		4		**4**
	20-24 weeks		2		**2**
	24-28 weeks		1		**1**
	28-32 weeks		1		**1**
	48-52 weeks	1			**1**

There is a significant wait between the first appointment and the second appointment where the service starts to actively work with the individual. As seen in Table 23 the second appointment takes over 52 weeks for the majority of children. As of February 2020 there are 72 children on the CYPS LD waiting list but with a new service specification being put in place and increased staffing, it is anticipated that waiting times will improve and support will be accessed in a more timely manner.

Table 23 – Wait time to second contact (March 2015 - March 2019)

Team	Wait Time	2017/18	2018/19	2019/20	Grand Total
CYPS - LD Service	0-4 weeks	12	7	1	**20**
	4-8 weeks	6	6	2	**14**
	8-12 weeks	6	7	6	**19**
	12-16 weeks	4	2	3	**9**
	16-20 weeks	4	1	4	**9**
	20-24 weeks	3	2	1	**6**
	24-28 weeks	1	3		**4**
	28-32 weeks	2	2	1	**5**
	32-36 weeks		**3**	**1**	**4**
	36-40 weeks	2	**2**	**3**	**7**
	40-44 weeks	2	**2**	**1**	**5**
	44-48 weeks	1	**1**	**1**	**3**
	48-52 weeks	3	**1**	**2**	**6**
	Over 52 weeks	30	**45**	**22**	**97**

2.7.8 Transitions

Where a child with a learning disability is deemed to need further support in adulthood they will transition to adult services. Most children who transition are already known to the Disabled Children & Young People Service (DCYPS). In 2017-18 8.28% of young people aged 15-19 years known to DCYPS transitioned to adult services.

More detail on Transitions is included in Section 8 of this document.

2.8 Challenging behaviour

Challenging behaviour is defined as:

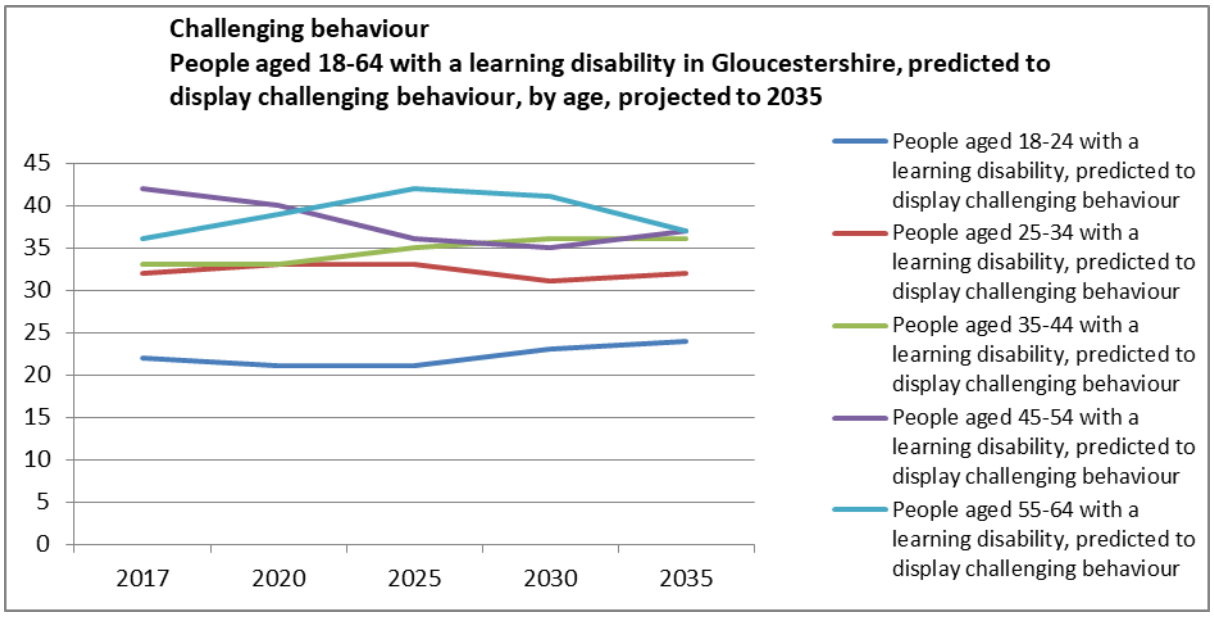
> *'Behaviour can be described as challenging when it is of such an intensity, frequency, or duration as to threaten the quality of life and/or the physical safety of the individual or others and it is likely to lead to responses that are restrictive, aversive or result in exclusion.'*

Source: Royal College of Psychiatrists, British Psychological Society, Royal College of Speech and Language Therapists, (2007), Challenging behaviour – a unified approach.

2.8.1 Prevalence

The number of people identified as challenging to services in any given area is unconfirmed. Estimates vary, but it is likely that about 24 adults with a learning disability per 100,000 total populations present a serious challenge at one time. This would translate to approximately 200 people in Gloucestershire[7].

Chart 10 - Projections by age for those with an LD exhibiting behaviour that challenges



[7] Caveat - PANSI only provides prevalence within LD cohort, and not ASC. So this figure is an under representation.

There were 38 admissions[8] to specialist Learning Disability Assessment & Treatment Inpatient beds in Gloucestershire during the period April 2010 to September 2014, an average of 8 people per year. Between October 2014 and September 2018, there were 6 (CCG) and 6 (Secure/NHS England) admissions.

There are 10 people within LD flagged as "at risk of admission" to a specialist learning disabilities in-patient facility and these are considered within the Dynamic Support process that the Transforming Care Programme locally has been undertaking.

2.8.2 Services in use

Social care records identify that there are 84 individuals in receipt of services from Gloucestershire County Council who have complex needs and behaviors that challenge services.

Table 24 Services for people with behaviours that challenge services by district

Sum of Number of service user	Cheltenham	Cotswolds	FOD	Gloucester	Stroud	Tewkesbury
People with complex needs and behaviours that challenge	54	5	24	20	19	7

SOURCE: GCC Performance & Need

Table 25 - No. of Service Users Out of County with behaviours that challenge services by year

Sum of Number of service user					
Categories	31/03/2014	31/03/2015	31/03/2016	31/03/2017	31/03/2018
People with complex needs and behaviours that challenge	5	6	6	7	8

[8] Under the Mental Health Action Section 2 or 3.

The CCG funds support to meet the health needs of a number of people via either Continuing Health Care (CHC), joint funding arrangements (either via Section 117 of the Mental Health Act or Section 256 of Health Act Flexibilities) or via NHS provider commissioning arrangements.

- Residential Provision: 58 individuals
- Supported Living Provision (including Direct Payment: 70 individuals
- Standard CHC – not Fast Track: 92 people
- In-county in-patient specialist LD (Health & Care NHS Foundation Trust): 6 people
- Out of county in-patient specialist:13 people

There are an additional 17 people funded by Specialist Commissioning (NHS England) who will at some point need to step down to the community.

With regards to individuals currently receiving care and treatment in long stay hospitals, where Gloucestershire has responsibility.

- 56% have a dual diagnosis of Learning Disability and Autism
- 8% have a learning disability and suspected autism.
- 8% have a diagnosis of Autism with no LD.
- 28% have a learning disability.

Research repeatedly shows that all behaviour is meaningful and will serve a purpose for the individual. Challenging behaviour is frequently the symptom of unmet needs, and often becomes the most reliable means an individual has of communicating this. Developing an understanding of when and why an individual uses their 'challenging' behaviour is fundamental to providing effective support. This understanding will enable professionals to work proactively to reduce the risks. This will also identify the necessary skills needed to help the individual develop in order promote long lasting and meaningful behaviour change.

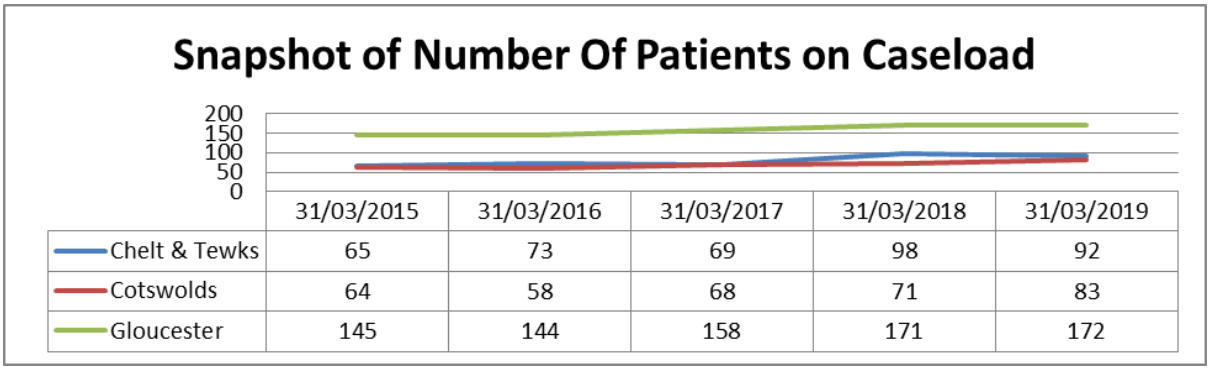
Around 6 young people with learning disabilities and/or autism with challenging behaviour enter residential care each year.

There are currently 19 children and young people in residential care placements at an average cost of £217,000 per year. At present 9 out of the 19 individuals placed in residential schools are placed out of area. The young people are on average placed in a residential school at the age of thirteen and a half. This is consistent with national trends and correlates with the age when a child's difficult behaviour is exacerbated by an increased physical size and the effects of puberty. As young people move towards adulthood, there is a need to prepare them for adulthood early on, to avoid young people ending up in crisis once they have turned 18. This will be a focus of the County Transitions Strategy in development.

The number of children who challenge services are believed to be increasing.

- The numbers of young people who challenge services and are in transition to adulthood are believed to be increasing. In 2014/2015 the CYPS LD Team accepted 105 referrals, 12 of these were for support with high levels of challenging behaviour.
- In May 2015 Gloucestershire Health & Care NHS Foundation Trust Child and Adolescent Mental Health Service Learning Disabilities Team (CAMHS LD) had a total of 281 children on their caseload. Of these 18.5% have high levels of behavioural challenges and 49% have behavioural difficulties where the team are involved to assist in the prevention of behaviours becoming established. 32% of these cases are considered early intervention.

Chart 11 - Snapshot of patients on CAMHS LD caseload by locality (March 2015 - March 2019)



	31/03/2015	31/03/2016	31/03/2017	31/03/2018	31/03/2019
Chelt & Tewks	65	73	69	98	92
Cotswolds	64	58	68	71	83
Gloucester	145	144	158	171	172

Chart 12 - No. of patients on CAMHS LD caseload split by age (March 2015 - March 2019)

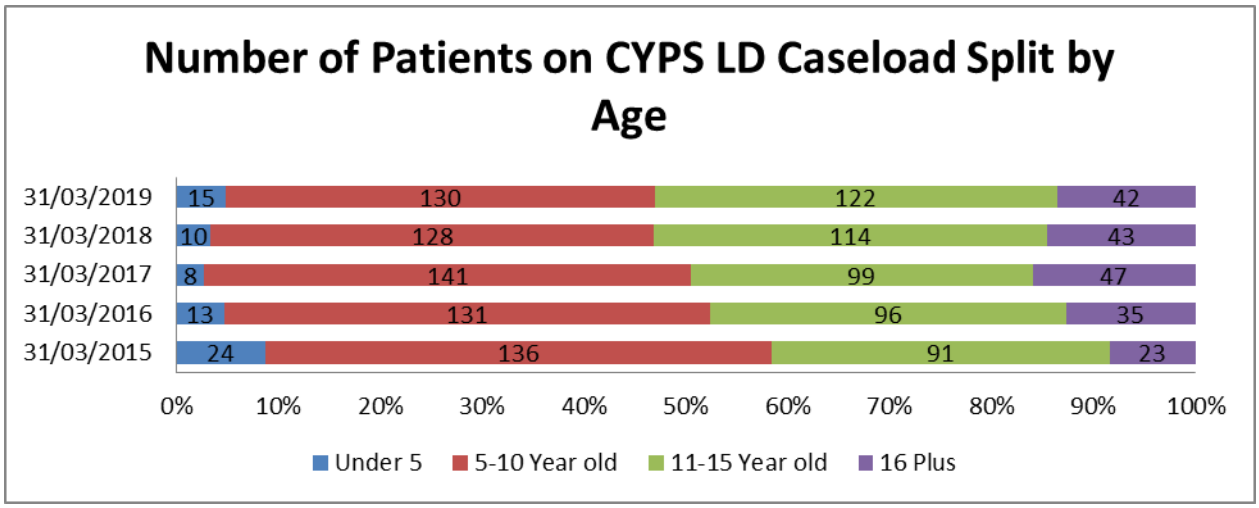
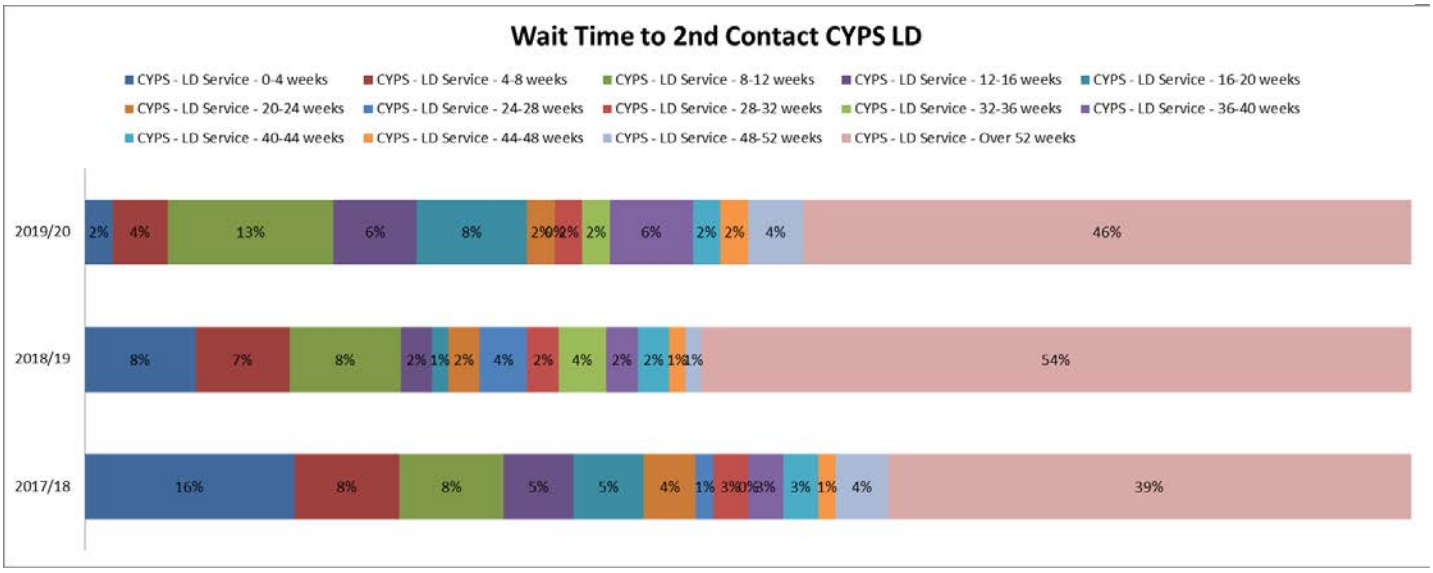


Chart 13 - Wait time to 2nd Contact for CYPS LD Service



2.9 Recommendations

Adults

- **ASC Data recording:** work with primary care to increase the % recorded. ASC diagnostic service to write to GP to get read-code added onto their system. Include this in the next ASC Audit. Ensure the ASC Strategy Subgroup on Data includes this within their remit.
- **Annual Health Checks:** AHC coverage to be consistent across all localities
  ASC post diagnostic support: better support required post diagnosis to meet the needs of people of all ages.
- **ASC Diagnostic team waiting times:** to meet national guidelines for waiting times (3 months vs current performance of 14 months).
- **Challenging behaviour strategy:** is reviewed and updated.
- **Lifestyle related conditions:** – reduce inactivity and improve access to mainstream healthy lifestyles services.
- **Dysphagia:** early detection of dysphagia and active management plans – including workforce training to support this.
- **Diabetes:** work with Diabetes CPG – workforce knowledge and competency to manage this in the community and prevention of type 2.
- **Cancer screenings:** variation in uptake – need to verify data. Work with national cancer screening programme and the Cancer CPG to address health inequalities gap.
- **Use of anti psychotic drugs:** STOMP to include ASC - Work with audit to include appropriate read-codes.
- **Market shaping:**
  - Projections – older adults forward planning for accommodation support.
  - Projections – Children transitioning to adults – forward planning – better transitioning between services including system interfaces. Can Education Psychologist inform GPs when they diagnose LD or ASC condition, standard letter templates with GP read codes included.
  - Projections – Those with forensic needs being discharged from secure settings will need appropriate accommodation support with staff who have the right skills.
- **Workforce knowledge and skills:** Prevention and management of diabetes and Chronic Heart Disease and other long term conditions are key, ensuring that the specialist workforce are skilled in prevention and management of these conditions will be fundamental to reducing early deaths.

Children

- **Wait Times:** Reduction in waiting times for both Autism diagnosis and the Child and Adolescent Mental Health Service Learning Disabilities Team CAMHS LD assessment and intervention services.
- **NICE Compliance:** Develop multi-disciplinary teams for all ages 0-18 to diagnose ASC in line with NICE guidance.
- **Lead Professional/Key Worker Role:** to develop this role further so that there is one point of contact for children and their families whilst awaiting diagnosis and beyond.
- **Pre diagnostic support:** Early intervention for children and young people within universal and targeted services.
- **Post-Diagnostic Support:** Increase in post-diagnostic support for children and young people with autism and their families to meet their needs and ensure they understand what their diagnosis/non diagnosis means.
- **Transitions:** Improving preparation for adulthood (ideally from 14 years old) to begin getting ready for their transition into Adult Services or discharge into universal services such as the GP.
- **Reduction in exclusion rates for children identified with SEN:** Ensure settings and schools have training to be able to support children and young people with a learning disability and or autism.
- **Out of County Placements:** Support young people coming back into County, particularly when they are also transitioning into adult services. In addition, to develop the market to be able to support children and young people within their community and prevent out of county placements where appropriate.
- **Dynamic Support Register and the Early Identification and Intervention Tool:** Ensure that the children's workforce is trained to understand the dynamic support register so that they are able to highlight when a child or young person is at risk of hospital admission (tier 4) and promote earlier intervention.
- **Child's record:** To develop the digital strategy to improve joined up data sets to inform actual prevalence data and to support commissioning for those with LD and/or ASC.
- **Workforce development:** To improve the children's workforce knowledge and understanding of LD and Autism to better support children as they move through the system / continuum of need.
- **Mental health support:** To work with mental health commissioners to monitor accessibility of mental health support in mainstream schools for children and young people with

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Learning Disability & Autism

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Learning Disability & Autism Strategic Needs Analysis

2018-2019

CHAPTER 3

Do people with LD &/or autism feel supported to have a good and meaningful everyday life?

3. Do people with LD &/or autism feel supported to have a good and meaningful everyday life?

3.1 Key Findings

Around **20%** of people who are known to Adult Social Care with a learning disability are in paid work.

Since 2015 **83%** of people supported by Forwards have remained in work for more than **52** weeks.

The proportion of people with a learning disability who feature on the SALT (Short and Long Term Support) return locally is **6.4%** compared to **6%** national average. This figure is only for people who are receiving long term services (although the title contradicts this) and it does not include those who are receiving support from Enablement or Employment services.

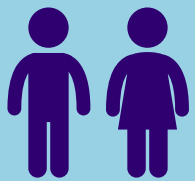
Forwards support an average of **50** people into work each year. Most of these will have a learning disability or autism.

Only **3.37%** of learning disability services reviewed in 2018 fell outside of the 'happy to live there' or 'happy to live there with minor changes' scoring categories

Proportion of disabled people in work compared is **48%**. In the general population, this figure is **80%**. The Government are looking to address this by pledging to help one million disabled people into work by **2027.**

Further support people to manage finances and paperwork themselves (only **4.1%** reported they could do this themselves)

We are now starting to see an increase in young people with higher functioning autism taking part in AIM



Common barriers to exercise were reported as **lack of transport** to and from suitable activities, particularly in the Forest of Dean and the Cotswolds.

3.2 Services & Activities

Our Engagement survey found that many people with learning disabilities and/or autistic spectrum conditions were supported to do the hobbies and activities that were important to them. People in Gloucester told us that they were able to access a variety of hobbies such as **dance, football, swimming, singing, volunteering and education.** However, children and young people, people with autistic spectrum conditions without learning disabilities, and people in more **isolated areas** such as the Cotswolds reported poor access to hobbies and activities. For example, one parent wrote:

"I keep seeing how fabulous inclusion is and how Gloucestershire is working completely towards inclusion BUT you are neglecting a small minority who really need support. There are no really safe playgrounds to take my daughter to, no easily accessible sensory rooms, no play barn sessions for her. If we lived in Stroud we would have things but we live in the North Cotswold."

The majority of children and young people with a learning disability and/or autism will be attending an education setting[1] . This provides a structure to their day and opportunities for learning and interaction with their peers. There are also out of school clubs available including, art, sports and youth clubs, along with others. However, as these young people become adults, opportunities need to be identified to enable them to continue to learn and play an active role in their community. In particular, young people that have been in out of county residential placements, often struggle with transitioning back into Gloucestershire to access adult services as there is a lack of support and daily structure for them here.

3.3 Self-Care & Prevention Support

We asked people if they had the support they needed to eat a healthy diet and to engage in exercise

53% said that they had the support they needed to eat healthily.
43% said that they were able to exercise regularly.

The common barriers to exercise were reported as **lack of transport** to and from suitable activities, particularly in the Forest of Dean and the Cotswolds, and **lack of coordinated care** at the activity itself. For example, one young person from a special school we visited in addition to gathering our survey responses told me that he had a space at an after school activity club waiting for him and he had transport available to get him there. However, there was no 1-1 available for the time of the session and no transport available to get him home and so he couldn't take the place.

[1] Gloucestershire's Joint Strategy for Children and Young People with Additional Needs, including Special Educational Needs & Disabilities (SEND)

https://www.gloucestershire.gov.uk/media/2083685/**jointstrategy29october_18.pdf**

More positively, several people told us that their GP had provided them with subsidised gym and slimming club membership that they were using regularly to positive effect, and the majority of the people we spoke to understood the principles of healthy eating; suggesting that educational drives are having a positive impact.

"My Dentist is a good man. I do zumba and dancing and yoga, swimming and sometimes football and carriage driving."

– adult with learning disabilities and autism.

3.4 Employment

Gloucestershire has a range of employment initiatives aimed at helping disabled people and people with long term health conditions to secure and sustain work. Most of these are aimed at helping people find paid work however Forwards is currently undertaking a 12 month project aimed at helping young people with complex disabilities who are in education and about to leave education to find unpaid placements in their community.

In 2015 Gloucestershire County Council awarded funding to set up Forwards Supported Employment Service working with people of all ages and across all disabilities to find paid work. Since then we have seen momentum grow with new projects being introduced and a marked change in attitudes towards employment for people with learning disabilities and autism.

In 2015 we also introduced supported internships with one provider – Gloscol. Due to the success of the first year where 10 of the 12 students found work we then expanded the programme to include other providers. We now have 5 providers offering this as part of their post 16 provision.

Realising that there were still gaps in provision in 2016 we secured £3.2m Big Lottery and European Social Fund (ESF) to develop a programme for people who are furthest away from the labour market. The model was based on the one we used for our Forward service but expanded to reach groups who Forwards did not have the capacity to work with. This included people with autism and learning disabilities who are not known to adult social care and who may "fall between services".

Gloucestershire is unique in its offer of employment support in that it is cohesive. GEM is a partnership of over 30 organisations with interventions offered in the local community. It is delivered mainly by the VCSE sector. All of the GCC-led programmes/services work together strategically and operationally allowing people to access provision which is most appropriate to their needs. Additionally other programmes funded by ESF or DWP work collaboratively along with DWP partnership managers and Jobcentre Plus Work Coaches. All of the provision offers support to both people with learning disabilities and higher functioning autism however dialogue between the delivery organisations means that there is recognition of expertise and referrals between programmes are encouraged.

The ***Better2Work*** Vocational Service provides an employment service for people in Gloucestershire experiencing significant mental health problems. Because of the specific service focus on helping people with serious and complex mental health problems, the team are located within Gloucestershire Health & Care NHS Foundation Trust secondary care clinical services and aligned to each of the Recovery Teams. ***Better2Work*** will work with those with a learning disability and/or autism; but the primary need must be the serious mental illness.

The ***Better2Work,*** Vocational Service is based on 'The Individual Placement and Support' (IPS) model for employment. The IPS programme is a supported employment service that helps people in community mental health services become part of the competitive labour market.

Case Study 1

S has a learning disability and has volunteered for many years however it was always his goal to gain a paid job and his Forwards Job Broker created a plan identifying the steps needed to achieve his aspirations.

Forwards arranged a work experience placement at Cineworld. S was very enthusiastic about this opportunity and met with the manager. S knew immediately that he wanted to work there.

To help S learn the role and undertake necessary training Forwards completed an Access to Work Application for in-work support. Before S started his placement he met with his Job Coach and his line manager and they discussed how long the placement is for, hours and the areas of support needed. S's Job Coach showed him how to complete tasks using Systematic Instruction, this method of learning is used by all Job Coaches.

S's passion and enthusiasm shone through and he proved during his placement he was an asset to the team. At the end of the placement S was offered paid employment however he still needed some support in specific areas of his role. An extension for his in- work support was requested and the Job Coach continued supporting S for a limited amount of time. S has now completed all training and is working without his Job Coach.

His employer said "S has adapted well to his role at Cineworld and is a valued member of the Gloucester team. He always has a smile for our customers and his colleagues. It really is a pleasure to work with him."

Case Study 2

A has higher functioning autism and came to Forwards after leaving college in 2018. A had volunteered previously however he and his family felt it was time to focus on seeking paid employment. The Forwards Job Broker met with A and his parents to discuss his career aspirations. A's parents did not think that A would be able to get a paid job or be independent within the community so the Broker developed a plan which would allow A to develop the skills he needed to develop his capacity for work.

The Forwards Employer Engagement Broker negotiated an opportunity at Smyths toy store and arranged for A to complete a work trial. The work trial was extremely successful and he was offered paid employment for the Christmas period.

A was responsible for a number of different tasks and received in-work support through the Access to Work Scheme. The Forwards Job Broker worked closely with the Job Coach and A's employer to ensure that A had a support plan which developed his skills and help the employer understand his needs. Over the period the job coaching support was withdrawn allowing A to work unsupported.

Following this work A continued to work with his Broker and is now looking to find paid work in a role which meets his aspirations and uses his qualifications. The temporary role at Smyths allowed him to build his confidence and skills and has helped him have a clear idea of what he now wants to achieve. Smyths have also said that if a permanent vacancy came up they would very much welcome an application from A.

A's employer said this "I found the experience working with A really beneficial. I found A was greatly suited to the role of the till bank as it takes a lot of concentration and diligence of which A's process of completing things suited. All A required from ourselves initially was time explaining things thoroughly and once he'd absorbed the information he was brilliant at putting that into practice.

A was also the best till operator in terms of dealing with the public. The way he spoke to them and thanked them came across as really genuine whereas a lot of retailers it comes across as robotic.

A blended into the team really well and whenever I spoke to my colleagues about how he was getting on they were highly complementary. After the initial support from the job coach we found that A became more and more self-reliant as the job coach was able to leave them to serve with minimal input. Given that the team haven't worked with many people with Autism it was a great experience for them and they realised that with only a little extra guidance A was more than capable of succeeding on his own"

What A said about his experience;

I really enjoyed my month before Christmas at Smyths. I found that I was able to work on the till as a cashier working with money even though I have little understanding of money matters in general.

My Smyths trainers and my job coach were very patient and helped me to pick up the job quite quickly. Once I understood the routine I was more relaxed. It helped my confidence to think that there are jobs out there somewhere (even though someone found it for me) if given the opportunity.

I don't think I made any important mistakes and I was lucky not to have any unpleasant customers to make the job stressful. I was able to learn a regular bus route and did not have any delays caused by bad weather or the Christmas queues.

The manager Paul was very kind and reassuring and helped me not to feel nervous. It was sad that I was not allowed to learn more about the retail business but I am hoping to collect a reference from him shortly that will start off my CV. I hope that something, at least part-time, will appear in the future but I know I will need a lot of support and help for it to happen.

Case Study 3

K has a severe learning disability with traits demonstrating behaviour of someone on the autistic spectrum.

K was offered a work trial with an employer however the location was not accessible via public transport. The nearest bus stop would mean they would need to walk along a severely overgrown and narrow pavement, frequently seeing them having to step into the road on a regular basis. This is a dangerous situation for K to be placed in and in any weather, therefore, we request a taxi service be funded for K's working days during the work trial, to ensure that they arrive to work safely and on time, and afterwards when he is offered employment. Access to Work approved in work support and taxi to and from work.

3.5 Employment - How do we monitor progress?

Part of the Forwards evaluation of our service is to monitor our customer's progress using a distance travelled tool we have developed called the "Forwards Flower" Completed at three month intervals this allows our customers to self-evaluate their progress. An example is in Appendix 3 – data tables.

3.6 Employment - What more can we do?

Employers: Key to the success of any employment service, programme or project we have successfully engaged with a number of employers through our work, however this is still an area where we have more work to do. We know stigma and prejudice still exists and we need to understand why employers don't consider disabled people, particularly those with learning disabilities and autism when they are recruiting. We are starting to look at this more strategically and have set up employer forums which will challenge employers and ask them what they need from us in order to open up more opportunities across all sectors and abilities.

GPs: We know GPs have precious little time to see people and we have not been able to successfully engage GPs in our work. If we can work with GPs across the county and they can refer in to Forwards or GEM we can reach people sooner and start working with them to build their capacity for work.

Education Providers: Again we have made good progress here around raising the aspirations of young people with learning disabilities and autism by engaging with special schools and our education teams in GCC. We still have more work to do especially reaching young people in mainstream schools and we continue to build on our relationships with teams who provide support.

Young people who are not in education, training or employment (NEET): This group of young people are extremely vulnerable and we know that in our NEET population there are young people with learning disabilities and autism who are children in care, care leavers, involved in offending and who may be homeless. We see this as a priority and we are working with partners to identify people who are NEET or at risk of becoming NEET to ensure that by reaching them earlier and provide them with the support they need.

Families and Carers and professionals: A young person often looks to their family for guidance. Sometimes aspirations are set low for an individual and sometimes they may have expectations. Often these aspirations are set at a young age by professionals around the family. We want to work closely with the family and their support networks to ensure that they understand what support is available and formulate achievable outcomes.

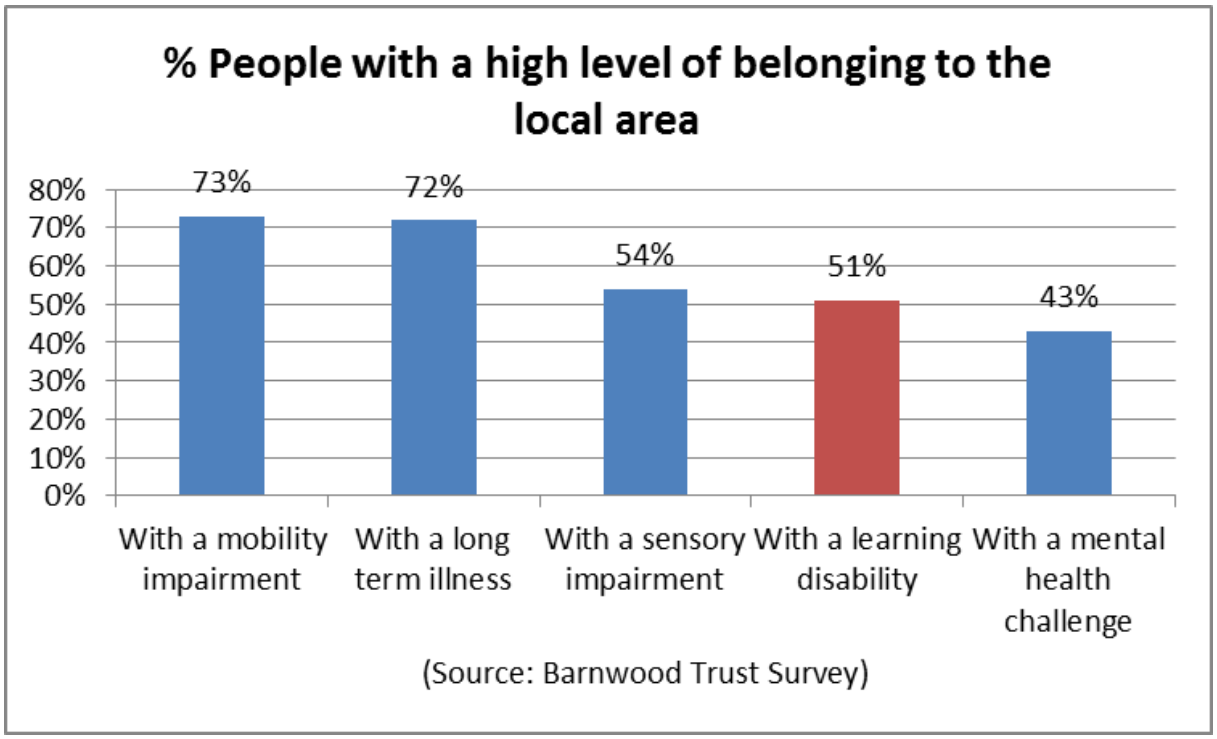
Benefits system: Often people will cite the risk of losing benefits as the reason for not taking up work. With the introduction of Universal Credit the Government aims to make it more feasible for people with disabilities and health conditions to work by introducing a flexible benefit system. However Universal Credit has been exposed to a lot of bad press about the pitfalls of the system and this has meant people have declined offers of work or have opted not to work with employment programmes. We are working with DWP to look at these challenges and have started to engage with individuals and families to understand what they need from us and DWP to allow them to access employment support.

3.7 Sense of belonging to a community

A survey by Barnwood Trust found that a person's disability type is associated with their sense of belonging to a local area. Compared with people with mobility impairment or other long-term illness, the survey found that people with a learning disability were less likely to have a high level of sense of belonging to their local area.

- 51% of respondents who had a learning disability reported a high level of sense of belonging to their local area.
- Among those with a mobility impairment or long-term illness, the equivalent percentages were 73% and 72% respectively.
- The group reporting a lower percentage than those with a learning disability condition was those with a mental health challenge, at 43%.

Chart 1 - % of people with a high level of belonging to the local area



(Source: Barnwood Trust)

3.8 Areas of life people with LD enjoy or value most

Table 1 - FACE Assessment - areas of life people enjoy/value most by cohort group 2016.

What our service users most value or enjoy in their life												
% Response	Top 3 areas	Top 4th & 5th	Others									
	Social opportunities	Family relationship	Hobbies	Edu and Employment	Relax	Independence	Access Community	Going out and about	Routine	Appearance	Other	Unknown
All responses	**32.4**	**42.4**	**46.7**	**2**	**52.1**	**5.5**	**3.9**	**29**	**6.4**	**1.8**	**17.7**	**4.6**
By primary support reason	Social opportunities	Family relationship	Hobbies	Edu and Employment	Relax	Independence	Access Community	Going out and about	Routine	Appearance	Other	Unknown
Physical support	**32.2**	**52.3**	**34.7**	**0.9**	**45.6**	**6.1**	**3.3**	**17.3**	**1.2**	**1.5**	**15.8**	**3**
Learning disability	**32.5**	**36.3**	**67**	**2.8**	**70.3**	**4.2**	**4.7**	**59.4**	**21.2**	**3.8**	**18.9**	**0.5**
Mental health	**29.4**	**30.1**	**54.6**	**3.7**	**42.9**	**9.2**	**4.3**	**28.8**	**3.7**	**0.6**	**17.8**	**8**
Sensory support	**73.9**	**52.2**	**43.5**	**4.3**	**43.5**	**0**	**13**	**34.8**	**0**	**0**	**26.1**	**4.3**
Support with memory	**29.9**	**41.5**	**37.2**	**1.2**	**51.8**	**3**	**2.4**	**12.2**	**1.2**	**1.2**	**18.9**	**9.8**

(Source: FACE Assessment, assessed in 2016 or 2017, as of 14 July 2017)

FACE Assessment of adult social care clients data (Table 20 - FACE Assessment - areas of life people enjoy/value most by cohort group 2016.) suggest that the most commonly mentioned areas of life that all service users valued/enjoyed most were

- 'To be able to relax/have quiet time'
- 'Having/keeping hobbies'
- 'Going out and about'
- 'Having a routine'

Service users whose primary support need was for learning disability also valued or enjoyed these aspects of life, but they were particularly more likely than other users to have valued or enjoyed 'Going out and about' and 'Having a routine'.

Regarding changes that service users felt would most improve their wellbeing or quality of life, the highest proportion (33.3%) felt they were 'Happy with their current situation/ arrangement' and did not want any changes.

Among those with a learning disability, the proportion happy with their current situation and not wanting any changes was even higher, at 41.5%.

Data within the ERIC Database for people with ASC is limited, as part of the Autism Strategy (2018-2021) there will be a working group set up to address this and reported through the ASC Partnership Board.

3.9 What changes would most improve wellbeing or quality of life

Table 2 - Face Assessment - what changes would most improve wellbeing or quality of life

What changes our service users think would most improve their wellbeing/quality of life										
% Response	Top 3 areas	Top 4th & 5th	Others							
	Happy with existing	Increase personal care / equipment support	Accommodation change	More control over life/ independent skills	Improve personal relationships / social contact	Education / training / employment	Healthy lifestyle	Personal appearance / hygiene	Unknown / unable to comment
All responses	33.3	10.3	14.9	9.2	26.4	2.9	8.6	2.2	14.4
By primary support reason	Happy with existing	Increase personal care/ equipment support	Accommodation change	More control over life / independent skills	Improve personal relationships / social contact	Education / training / employment	Healthy lifestyle	Personal appearance / hygiene	Unknown / unable to comment
Physical support	32	10.6	14.9	10.6	21.4	2.5	9	2.2	14.6
Learning disability	41.5	8	9	3.8	35.4	3.8	7.1	3.8	9
Mental health	23.6	9.3	22.4	15.5	24.2	3.1	13	0.6	13.7
Sensory support	30.4	13	8.7	13	56.5	13	8.7	4.3	4.3
Support with memory	35.3	13.3	16	6.7	22	0.7	5.3	1.3	24

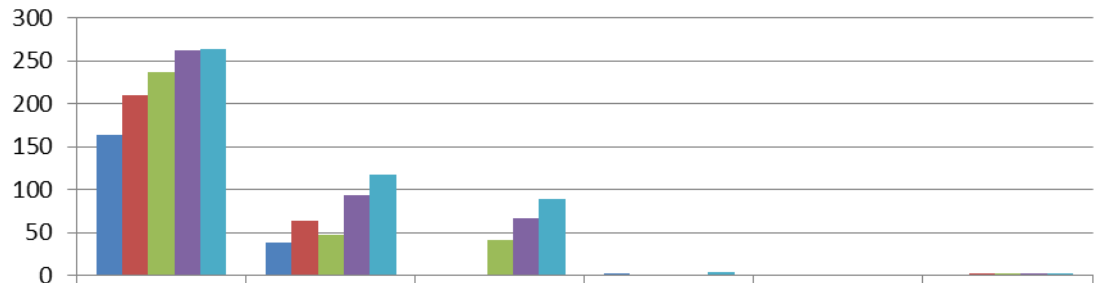
(Source: FACE Assessment, assessed in 2016 or 2017, as of 14 July 2017)

3.10 What self care & prevention support is available for people with LD & Autism (including Assistive technology provision)

There had been an upward trend in the uptake of Telecare and Enablement support services among adult social care service users whose primary support need is Learning Disability in the 5-year period between 2014 and 2018. This reflects the trends towards promoting self-care and independence.

Snapshot data suggests that the number of people whose primary support reason is Learning Disability receiving Telecare increased by 60.4% between 2014 and 2018 and the number receiving Enablement (all types) had increased by five-fold in the same period. Please note: Data on provision of another type of self-care support, Assistive Technology, are held by Gloucestershire Care Services, and not accessible on ERIC

Chart 2 - Number of adults with LD receiving self care and prevention support from Gloucestershire County Council



	Telecare	Enablement LD	Enablement Employment LD	Reablement Community	Reablement	Community meals
31.03.2014	164	39	0	3	0	1
31.03.2015	210	64	0	1	0	2
31.03.2016	237	48	41	1	0	3
31.03.2017	262	94	67	0	0	3
31.03.2018	263	118	89	4	1	3

3.11 How do people feel about the services identified meet their needs?

(Source: Adult Social Care)

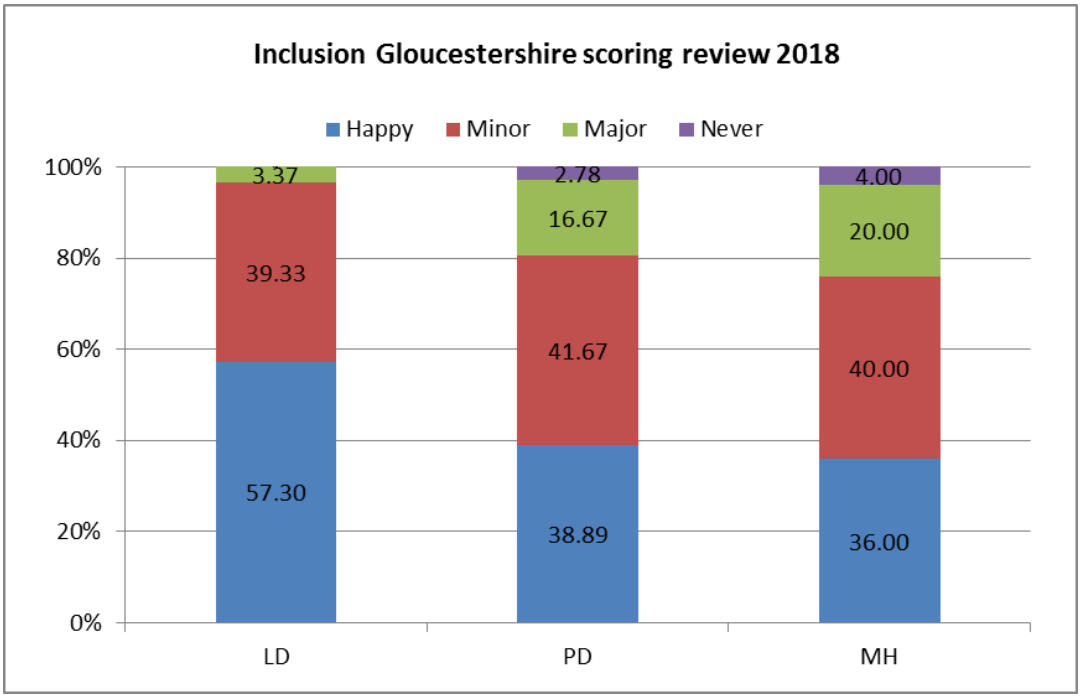
Results from the latest Adult Social Care Service User Survey 2017/18 suggest that in comparison with respondents with other disability conditions, respondents who had a learning disability were significantly more likely to be satisfied with the overall care and support services they received. They were also significantly more likely to be happy with the way care and support services had met a range of their needs, such as quality of life, control over daily life, independence, safety and feeling better about themselves.

The only area where a significantly lower proportion of respondents with a learning disability expressing satisfaction than those with other conditions was about dealing with finances and paperwork themselves. 4.1% of respondents with LD reported they could deal with these tasks easily themselves, compared to 15.6% of respondents with other conditions.

These statistics are supported locally when looking at the results from our peer-led quality reviews. The peer-led quality process focusses strongly on encapsulating the views and opinions of the individuals in receipt of care and support.

Only 3.37% of learning disability services reviewed in 2018 fell outside of the 'happy to live there' or 'happy to live there with minor changes' scoring categories, whereas across physical disability and mental health services this was far greater (see chart 7).

Chart 3 – 2018 scores from peer-led quality review



3.12 Recommendations

- **Employment:** Continue to develop employment offer and support people with LD and ASC into work. Recommend that the LD Partnership Board ensure that Job Centre has rolled out the 2 Ticks disability confident scheme.
- **Use of Technology:** Continue to explore use of technology enabled care.
- **Mainstream Healthy Lifestyles:** Support lifestyle services and leisure to be more accessible to those with learning disability and/or autism. Recommend that the ASC partnership board roll the Autism friendly approach.
- **Keeping Safe:** It is recommended that "The Keeping Safe Scheme"[1] be rolled out across more organisations in Gloucestershire and that all Partnership Boards sign up to this approach.

[1] http://keepsafeglos.org/safe_places/ **[Accessed 16.9.19]**

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Learning Disability & Autism

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Learning Disability & Autism Strategic Needs Analysis

2018-2019

CHAPTER 4

Is care for people with LD &/or autism person centred, planned, pro-active and co-ordinated?

4. Is care for people with LD &/or autism person centred, planned, pro-active and co-ordinated?

4.1 Key Findings

Direct payment take up has increased **2%** since **2014.**

Most families do not utilise the Carers Emergency Scheme **(3 users).**

59% of the people we spoke to felt that they were not involved in planning their care. This figure was higher in young people **(68%).**

People told Inclusion Gloucestershire as part of the engagement for this report that they **lack confidence** talking about what they want or need from their support, that they **often don't understand** how the payments work.

There was a lot of concern about the transition from children's services to adult's services, with family carers feeling that the progress they had made through stable interactions with children's services was being lost.

There are pockets of excellent support across the county:

76% of adults with comorbid learning disabilities and autism in Gloucester reported satisfaction with their support, as did **77%** of adults in the Forest of Dean.

221 services users whose primary support reason was LD had a Direct Payment, representing a **43.5%** increase compared to 5 years earlier.

4.2 Are people involved in planning their care?

59% of the people we spoke to felt that they were not involved in planning their care. This figure was higher in young people (68%) and so we spoke to the school council representing more than 300 children in a local special school about their understanding of the care they receive. We discovered that these young people, some of whom were due to leave school in the next few weeks, relied completely on their parents or family carers to organise their support. They told us that they lack confidence talking about what they want or need from their support, that they often don't understand how the payments work or what they can and can't afford to have, or that they don't know what they are entitled to. They also felt that their support preferred to talk to their parents or carers, and didn't place much value in their own thoughts about their care and support needs.

Similarly, parents of young children with complex needs described feeling dismissed or belittled, or of just not knowing where to begin.

"My support doesn't listen to me, they talk over me."

– young person with autism.

Parents said things like:

"I simply don't know where to start!" and "getting support is like getting blood from a stone!"

4.3 If someone's needs changed would they know who to contact?

The majority of people we spoke to felt that they knew who to speak to if they wanted or needed different support. In particular, those who were part of the "Shared Lives" initiative or engaging with "Life Services" were very positive:

"I would ask my support workers at life services for help with new support. I do activities I want to do with Life Services and if I want to try something new they seek with me. I go to respite a couple of times a year. Mum and dad help me with my budget/money. I feel I get enough support from all those around me. All professionals I see I am happy with; I am always supported to appointments. I get excited about going to respite (GL1), I am a really happy person. All carers support me to be independent."

– adult with lived experience.

However, there was a lot of concern about the transition from children's services to adult's services, with family carers feeling that the progress they had made through stable interactions with children's services was being lost.

4.4 Is the care pathway coordinated?

In order to capture people's experiences of the care they received, we broke this question down into multiple survey and workshop questions and explored the topic of support as follows:

We want to know about the help and support you have, things like:

- Do you have help to arrange your support?
- Can you choose how your support is paid for?
- Can you change your support or make other decisions about it?
- How happy or unhappy are you with your support?

One of the main issues that came to light is something the council is already aware of and working to address through initiatives such as "Proud to Care" and the "Glos Assistants Directory": namely a lack of people working in care services or as Personal Assistants.

People also told us about a lack of continuity, "I have had eight different support workers" and professionals spoke to us about difficulties organising individual care such as an "inconsistent workforce" or "it can be hard to get your support to change their focus with you". Overall, there seemed to be a feeling that no matter how your care was arranged or paid for, in reality the people accessing it have very little control over it.

"Very little choice with support. Social services seem to dictate what, when and how despite us having a direct budget"

– family carer.

We also heard about difficulties with **reliability of care,** and with **changing care** that wasn't working well for the individual in question.

However, there are pockets of excellent support across the county:

76% of adults with comorbid learning disabilities and autism in Gloucester reported satisfaction with their support, as did 77% of adults in the Forest of Dean.

"My support is not reliable. I didn't choose them, and I don't really like them. I haven't been able to change them. I give them 1/10."

– adult with learning disabilities and autism.

4.5 Direct Payments & personal health budgets

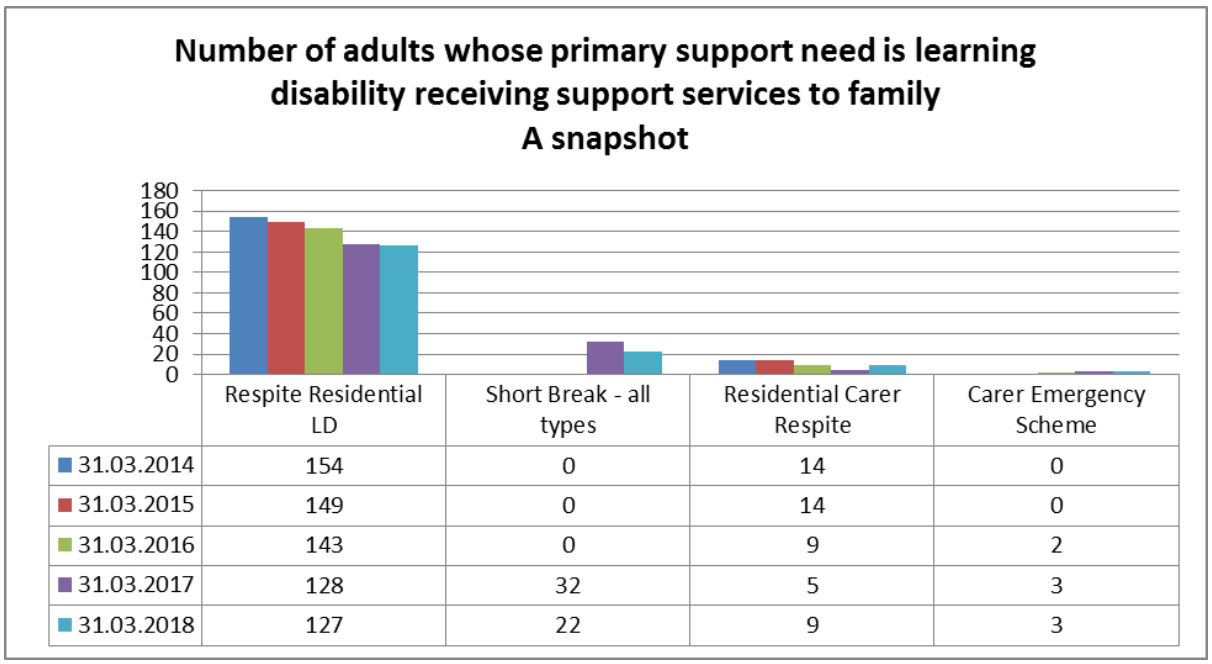
There has been a year-on-year increase in the uptake of Direct Payment by adult social care service users whose primary support reason is Learning Disability (LD) in the 5 years to 2018.

Snapshot data suggests that as of 31st March 2018, 221 services users whose primary support reason was LD had a Direct Payment, representing a 43.5% increase compared to 5 years earlier. This is only 15% of those adults known to social care with a learning disability compared with 13% known to adults' social care in 2014. See appendix 3 data tables for further information.

4.6 Support for family

The main support provided to family of adult social care service users whose primary support reason is LD is Respite Residential, but the provision has shown a downward trend, from 154 as at 31st March 2014 to 127 five years later. The number receiving Short Break is small, at 22 as of 31st March 2018. The number of carers registered with Carer Emergency Scheme was very low - no more than 3 at the last count on 31st March 2018.

Chart 1 - Support services for families for adults with a learning disability



	Respite Residential LD	Short Break - all types	Residential Carer Respite	Carer Emergency Scheme
31.03.2014	154	0	14	0
31.03.2015	149	0	14	0
31.03.2016	143	0	9	2
31.03.2017	128	32	5	3
31.03.2018	127	22	9	3

4.7 Recommendations

- Increase the number and opportunities for short breaks to support family carers. Explore Shared Lives as an opportunity to support families with respite care.
- Work with People Plus to increase the uptake of carers accessing the support schemes in Respite and Carer Emergency Scheme.
- Transition planning for children becoming adults – further embed the Ready, Steady, Go, Hello adapted document developed for healthcare and explore whether this can be utilised by social care as well.

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Learning Disability & Autism Strategic Needs Analysis

2018-2019

CHAPTER 5

Do people feel they have choice & control over how their health & social care needs are met?

5. Do people feel they have choice & control over how their health & social care needs are met?

5.1 Key Findings

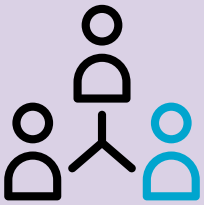
Easy-read materials provide great assistance and are empowering to the people that need them.

On-line services can be difficult to navigate and use.

28% of adults (or their carers) told us they knew about respite and how to get it.

From the engagement **0%** of children and young people and their carers did.

1 in every **3** people we spoke to felt that they had a choice about how to pay for the support they received.



All staff should be providing personalised reasonable adjustments to meet the needs of individuals with learning disabilities or autism.

Parents and Carers reported that they find Facebook groups for parents of children with additional needs really useful.

5.2 Is there enough suitable information in formats people can understand?

People told us that they are receiving more written Easy-Read information from services such as the NHS and the council, and that it helps them to understand appointments and information that they need to know. The people we spoke to were positive about this change and felt that Easy-Read information was empowering for them.

However, lots of people told us that online services such as the DLA website, YourCircle, and the Universal Credit online system were very difficult for them to navigate. This was particularly the case for adults who were living independently but still had significant care and support needs. Many people access the council drop-ins or Inclusion Hubs for help to read their letters.

5.3 Is there enough suitable information in formats people (inc. families with children) can understand?

Whilst there is no specific work to understand the provision of accessible information for people with an LD or ASC, work as part of the Inclusion Gloucestershire engagement events highlighted the needs of people with respect to accessing medical services, which includes information. The report stated that easy-read leaflets made accessing Primary Care easier.

Please note there is further information about Accessible Information in chapter 8.

5.4 Do carers & professionals have access to information to provide to people and their families? Do they provide the information?

Data from the latest Adult Social Care Service User Survey 2017/18 suggest that nearly 85% of adult care users whose primary support need was learning disability felt they had enough choice over their care and support services. This was much higher than the proportion reported by those whose primary support reason was for other health/disability conditions (59.6%).

On having control over life, 93.6% of those whose primary support reason was learning disability reported that care and support services helped them in having control over their life. This was also higher than the proportion reported by those whose support need was mainly for other health/disability conditions (87.0%).

Chart 1 - Choice and control over care and support services

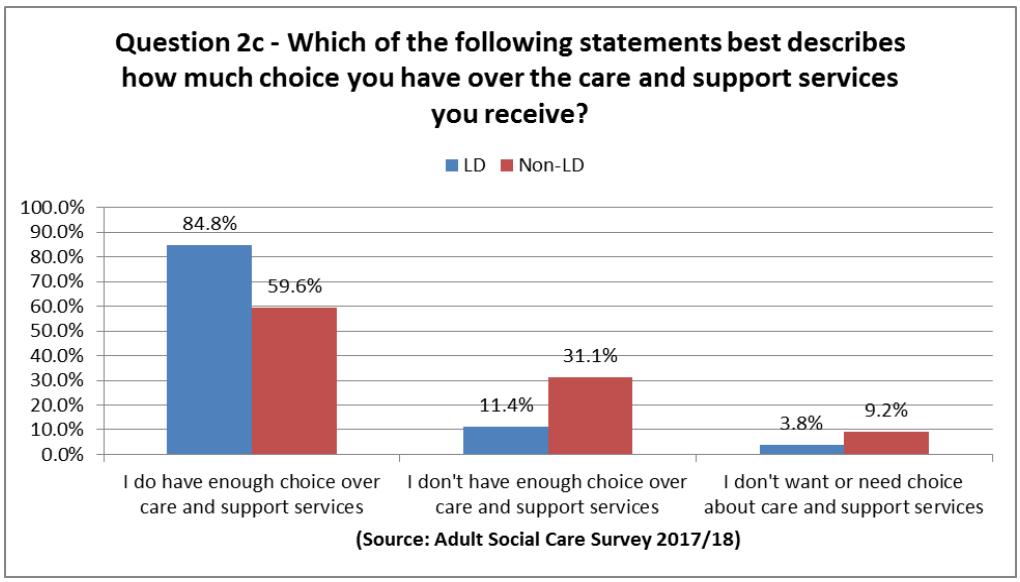
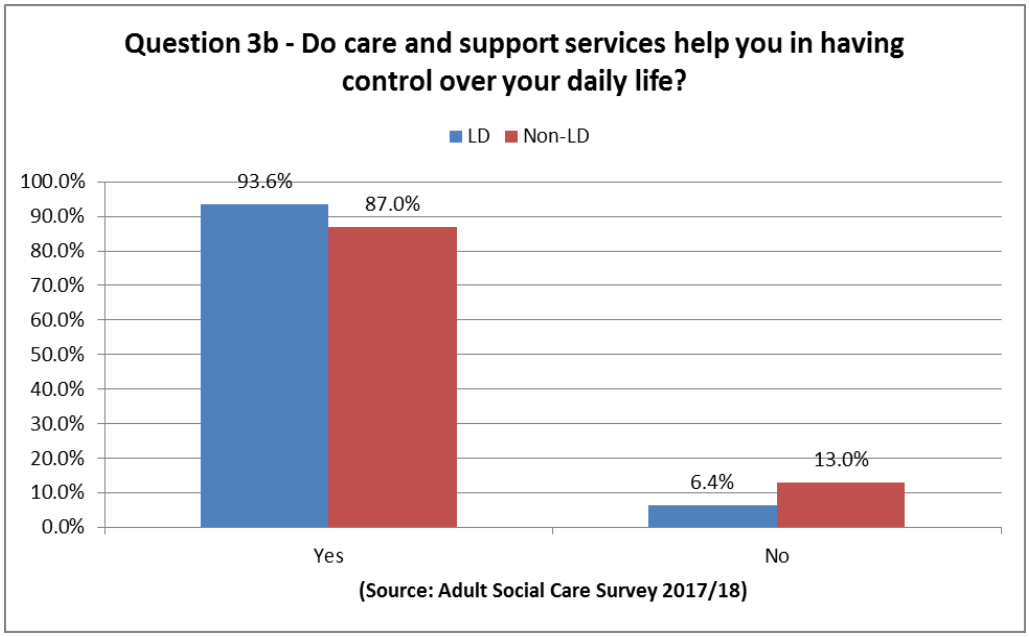


Chart 2 - Social care support services help people have control over their daily life



5.5 Do people understand how to access peer supporters and advocates?

All Local Authorities have a duty to provide independent advocacy in a number of specific circumstances to people who meet explicit criteria. In Gloucestershire, the advocacy service is provided by POhWER. It is for Adult Social Care & relevant NHS staff to identify when an advocate is needed and to arrange the provision of one. There are easy-read leaflets available.

The following information is from POhWERs annual report which highlights the amount of people with a Learning Disability who have accessed the service in the past year. People with a Learning Disability make up around a quarter of those accessing the service.

Table 1 - Number of people with a learning Disability accessing POhWERs advocacy service

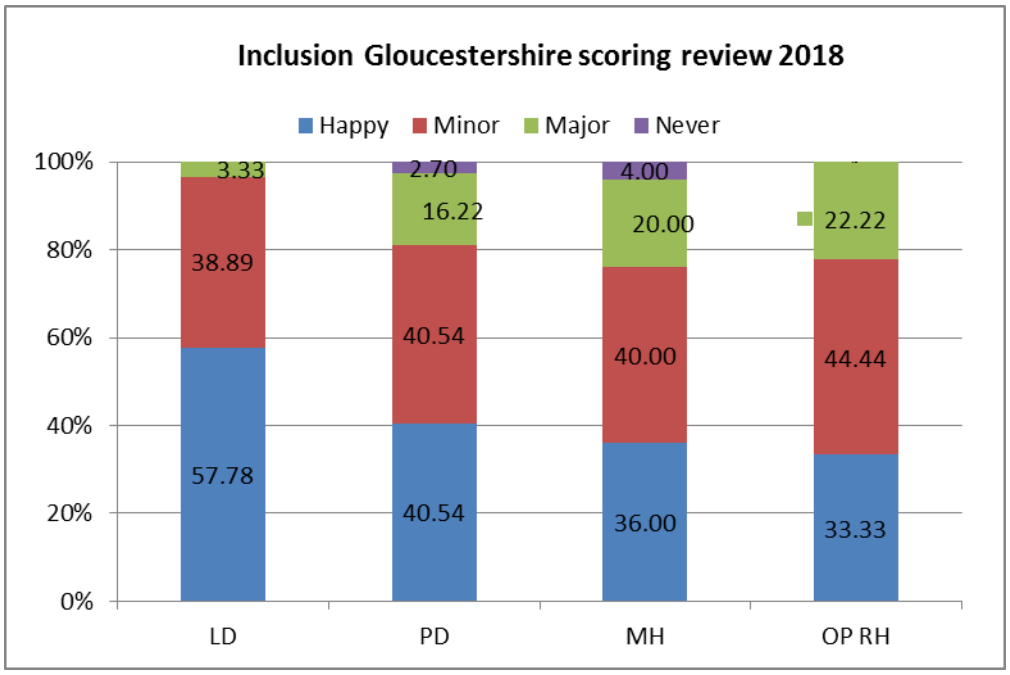
POhWER Gloucestershire Clients			
	Aug 2017-Mar 2018	Apr 2018-Mar 2019	Aug 2017-Mar 2019
Clients with Learning Disabilities	486	392	878
% of all clients	28%	20%	24%

Inclusion Gloucestershire are commissioned to provide peer review quality checks. In 2018, 90 visits were undertaken and all peer reviewers scored their visit as happy to live there, or minor amendments required.

Table 2 - Inc Glos Peer support scores 2018

Disability	Score	Out of County	Assessment & Treatment Unit	Day Centre	Residential Home	Supported Living	Total	Older People Res Home
LD	Happy	8	0	7	11	26	52	1
	Minor	5	1	6	8	15	35	1
	Major	0	0	0	0	30	3	0
	Never	0	0	0	0	0	0	0
Total:		**13**	**1**	**13**	**19**	**44**	**90**	**2**

Chart 3 - How learning disability compares with other disability groups



5.6 How do people use local NHS services?

Table 3 - Comparison of Gloucestershire NHS Services (averages) general Population vs Learning Disability

Average contacts with these services	LD	Gloucestershire norm	Difference
NHS 111	0.9	0.2	0.7
Community Services	3.6	1.1	2.5
Emergency Department or Minor Injury Units	0.6	0.3	0.2
Emergency Admissions	0.2	0.1	0.1
Emergency Admissions	0.1	0.1	0.0
GP Appointments	8.7	5.4	3.3

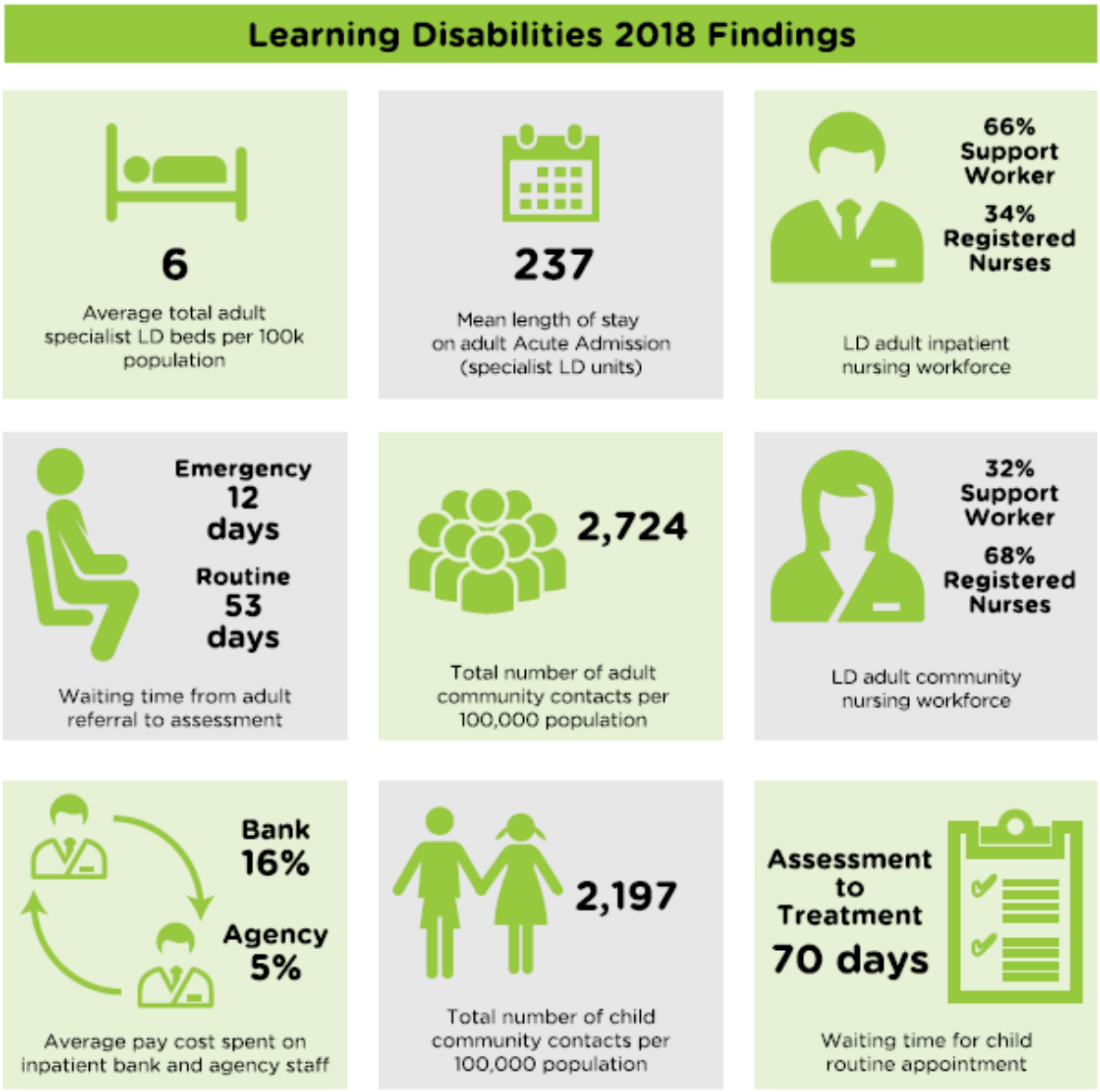
Table 3 - Comparison of Gloucestershire NHS Services (averages) general Population vs Learning Disability provides an overview of the averages that NHS services are utilised by the general population and gives a comparison against those with a learning disability (those with ASC only have not been captured from the data source). Admissions to hospital are equitable with those of the general population. Those with a learning disability in Gloucestershire are 3.3 times more likely to visit their GP than those without a learning disability and to use NHS Community Services 2.5 times more likely. Table 4 - Comparison by gender of utilisation of Gloucestershire NHS Services vs general population) gives an indication that females with learning disability are more 3.6 times more likely than the general population vs 1.7 times for male to utilise community services.

Table 4 - Comparison by gender of utilisation of Gloucestershire NHS Services vs general population

	LD		Gloucestershire Norm	
Averages	**F**	**M**	**F**	**M**
NHS 111	1.0	0.9	0.8	0.7
Community Services	4.7	2.9	3.6	1.7
Emergency Department or Minor Injury Units	0.6	0.5	0.3	0.2
Emergency Admissions	0.2	0.2	0.2	0.2
Elective Admissions	0.1	0.1	0.0	0.0
GP Appointments	10.8	7.3	5.5	2.0

The county average prevalence (based on Primary Care data) of those with a learning disability compared with the general population is 0.63%.

The county average prevalence (based on Primary Care data) of those with a learning disability compared with the general population is 0.63%. demonstrates that in Newnham and Westbury (Forest of Dean locality) this is 3.61% more than the county average (at 4.24% of the population of that district have a learning disability). At the bottom of this table is Broadway and Wichhamford (Cotswold Locality) who have no people with a learning disability within their population. This data cannot be viewed in isolation when planning and commissioning services but should be viewed in conjunction with Data tables use of Specialist Learning Disability Health services (Gloucestershire Health & Care NHS Foundation Trust – previously 2Gether NHS Foundation Trust).



The Local Picture

The following tables/ charts are copied from Gloucestershire's bespoke report and compares Gloucestershire's position (indicated in RED) against the national average (quoted statistic highlighted in green: for each of the 9 summary statistics above.

National:

6

Average total adult specialist LD beds per 100k population

Mean number of beds per 100,000 registered population				
Bed type	2gether	2017/18		2016/17
High, medium & low secure forensic	0.0	1.6	↓	1.7
Acute admission (specialised LD units)	1.2	1.2	↓	1.3
Acute admission (generic MH settings)	30.8	2.7	↓	3.1
Forensic rehabilitation	0.0	0.1	↓	0.2
Complex continuing care/ rehabilitation	0.0	1.0	↓	1.3
Other beds	0.0	0.4	–	0.4
Total beds	32.0	5.8	↓	6.0

National:

237

Mean length of stay on adult Acute Admission (specialist LD units)

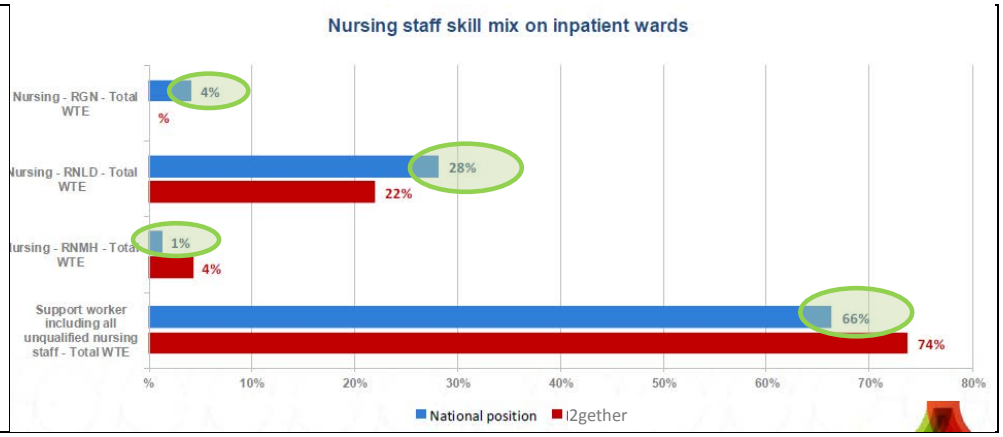
Average length of stay						
Bed type	Discharges			Current inpatients		
	2gether	2017/18	2016/17	2gether	2017/18	2016/17
Medium secure	-	482	534	-	496	616
Low secure	-	852	806	-	869	938
Acute admission (specialised LD units)	1042	237	230	3458	413	551
Acute admission (generic MH settings)	131	23	5	-	40	0
Forensic rehabilitation	0	0	336	-	190	639
Complex continuing care/ rehabilitation	0	649	1036	-	1177	1910
Other beds	0	174	49	-	278	1360

National:

66% Support Worker

34% Registered Nurses

LD adult inpatient nursing workforce

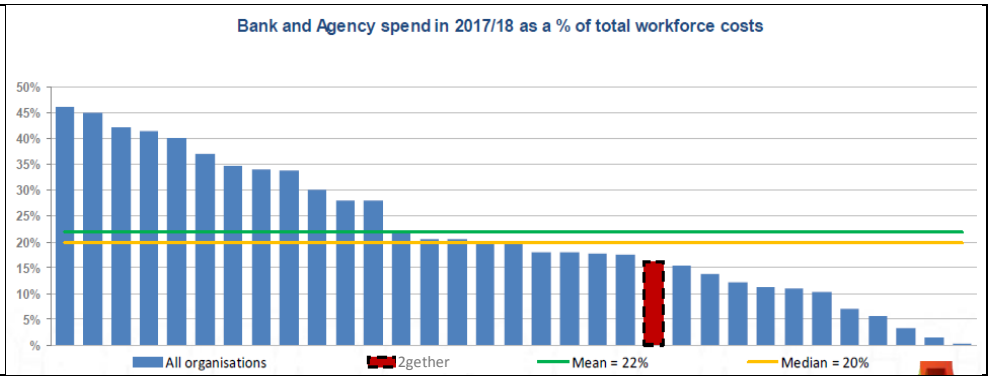


National:

Bank 16%

Agency 5%

Average pay cost spent on inpatient bank and agency staff



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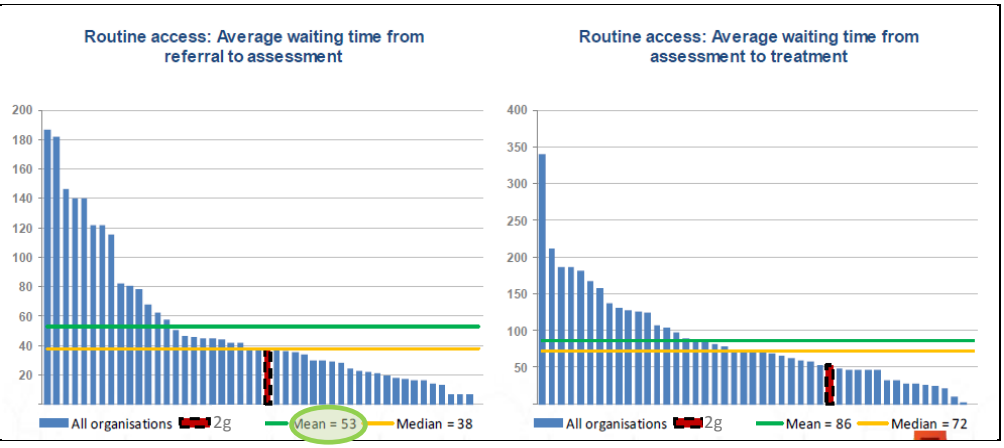

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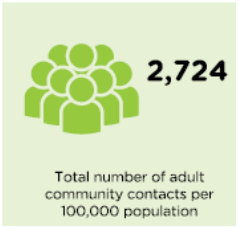

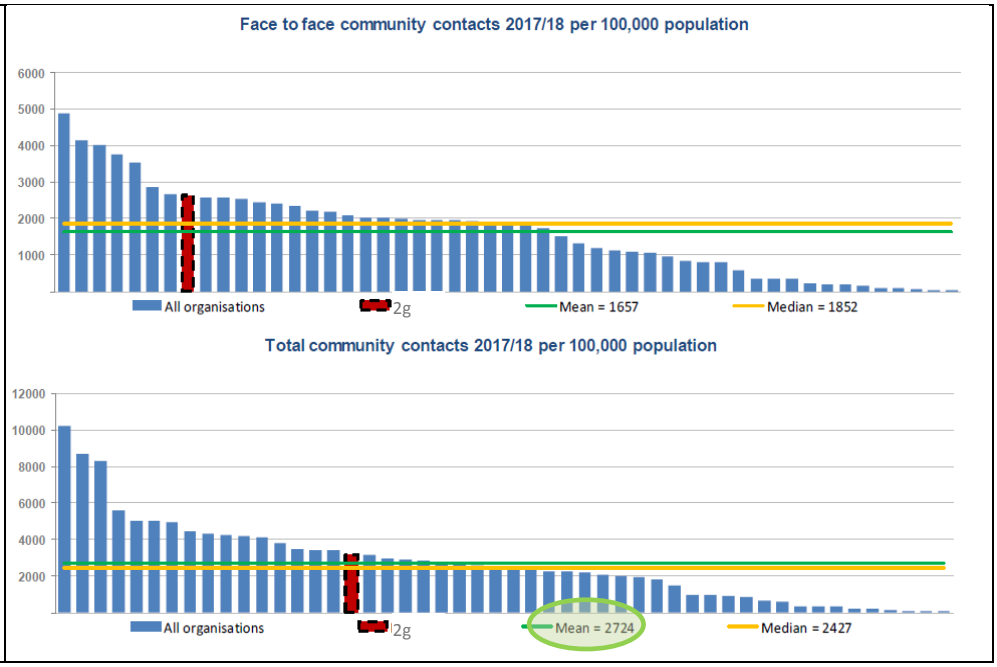

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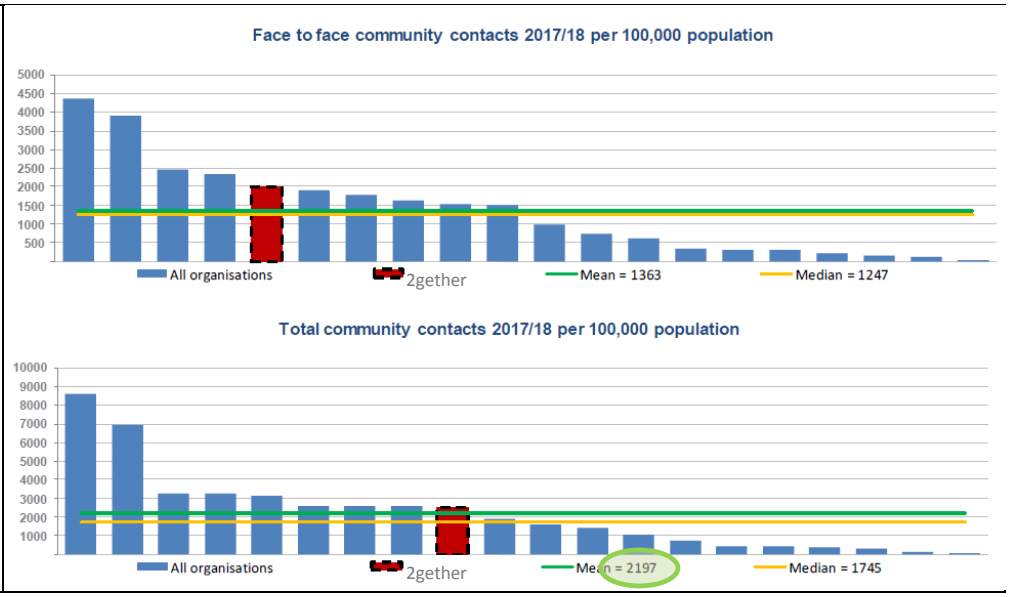

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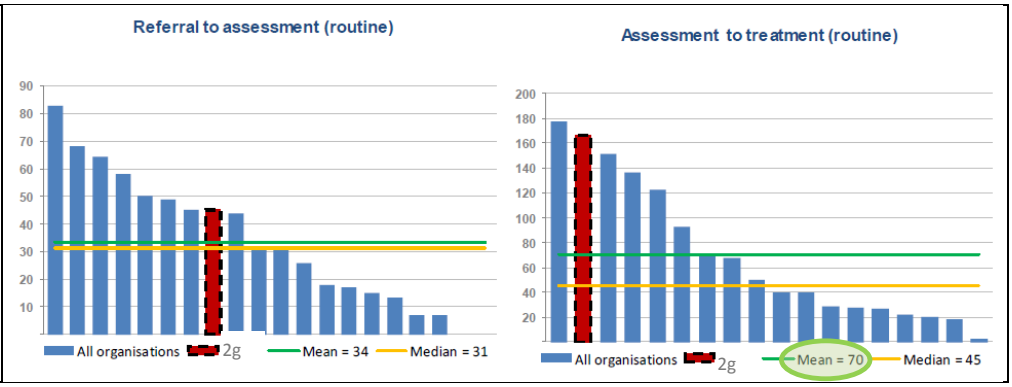

As of 31/3/18 there were 1596 patients with a Learning Disability open to Learning Disability Teams within GHC (Previously 2Gether NHS Foundation Trust).

People with learning disabilities experienced use of restraint in 2017/18 by specialist NHS provider within Gloucestershire - 5 in LD Assessment & Treatment Inpatient Unit and 37 in Community settings.

It should be noted that a large number of interventions carried out in the community settings, whilst restraint, were to support reasonable adjustments; e.g. phlebotomy procedures in the persons best interest, and achieved in a seated position.

5.7 Recommendations

- **Reasonable adjustments:**
  1. Locally to support NHS England and NHS Digital to develop a Reasonable Adjustment Electronic flag on the patient record systems summary care record.
  2. Training for all staff on communicating with and providing reasonable adjustments for those with a learning disability and/or autism.
  3. An audit is conducted on the accessibility of all Health and Social Care websites to ensure accessibility for those with learning Disability and/or ASC.
- **NHS Improvement Standards:** Staff recruitment processes, ensuring people with LD and or Autism participate in staff recruitment and induction for all health and social care organisations.
- **Facilities and estates to meet the needs:** Adult changing rooms "Changing places" for people with LD and/or autism in NHS and social care waiting areas.
- **Access to education:** Further support to help people access literacy courses run by the Adult Education Service.
- **Improved pathways:** Wider review of the children's learning disability and autism pathway/process was to understand reasons for long waiting times and develop recommendations to reducing waiting time length.

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Learning Disability & Autism Strategic Needs Analysis

2018-2019

CHAPTER 6

What support is available to family and paid support staff?

6. What support is available to family and paid support staff?

6.1 Key Findings

Just over **a quarter** of adults or carers were aware of the support available to them.

Over **three quarters** of people surveyed weren't aware of direct payments or personal assistants.

None of the families or carers of children with an LD or ASC knew about support and respite.

The local authority has a range of accommodation available to use for short breaks and respite.

Ensuring a sustainable workforce is a key issue for the future.

There are around **5,900** jobs in LD and ASC services in Gloucestershire within the local authority and CQC independent sectors.

Around **27%** of the LD and ASC workforce in Gloucestershire has engaged with the Care Certificate – either completed or in progress/partially completed. This is lower than both the South West and England averages (both **31%**).

6.2 Is it easy to find out what is available?

Only 28% of the adults or carers of adults we spoke to, including staff at special schools, were aware of the respite and carer support available to them and knew how to access it. 0% of the families and carers of children or young people with learning disabilities and/or autistic spectrum conditions knew about support and respite, or how to access it.

> *"We don't get any real respite. I haven't slept through the night in 17 years."*
>
> **– Parent of a young person with profound learning disabilities and autism.**

6.3 Can you choose how your support is paid for?

78% of the people we spoke to didn't know about direct payments or personal assistants, and they didn't know how to ask for more support when support needs changed following further illness or deterioration in the condition of the individual with care and support needs. Again, we understand that this is a current priority of the Direct Payments Team and would expect to see an improvement in this number by the next Joint Strategic Needs Analysis.

6.4 What is currently available e.g. short breaks/respite, alternative short-term accommodation?

Table 1 - Services currently available to support carer breaks

	Learning Disability and ASC
Short breaks	Self-contained 2 bed unit in Cheltenham available for short breaks. Local authority staff can be used for adults, but it can also be used by external providers for both Adults & Children subject to an occupancy agreement being signed. Hartwood House provides short breaks for up to 6 children, between the ages of 8-18 with a disability. There are a variety of activities offered, including cinema trips, artwork and shopping. Family Link Plus offers daytime and overnight care to children with disabilities and complex health conditions. The carers are employed by GCC and usually support these children within their own homes.
Short breaks	3 overnight beds learning disability autism services, with a total current usage of 96 service users. 2 beds available for spot purchase overnight respite in the Forest of Dean within a residential care home. Suitable for those with mild/moderate LD and PMLD.
In-house Respite	3 units within the county (Gloucester, Cheltenham & Stroud) for those with mild, moderate and severe LD, PMLD and autism, managed by GCC providing a total of 20 beds to 91 clients. These units can also be available for short term emergency accommodation.
In-house Day Opportunities	1 day opportunities centre (Woodlands – Cheltenham) for up to 6 individuals per day who have a learning disability and/ or autism who display behaviour that may be deemed as challenging. 5 centres within the county managed by GCC providing day opportunities for 97 people with LD, PMLD and Autism.
Other Day Opportunities	There is a wide range of providers offering other day opportunities and short breaks across the county. This list is not exhaustive of the opportunities available within Gloucestershire but does detail those currently purchased by GCC: • Allsorts • Active Gloucestershire • Active Impact • Aspirations Care • Building Circles • Crossroads Care • Forest Pulse • Glo-Active • Guideposts Trust • Home Farm Trust • Inclusion Gloucestershire

	• Jamats • Kingfisher Treasure Seekers Trust • Lower Kilcot Farm • L.I.F.E Services • Orchard Trust • P.A.C.E • Royal Mencap • SHARP • St Vincents & St Georges • Seven Springs Play & Support Centre • Selwyn Care • St Roses School • Salters Hill Charity • The Spring Centre

(Source: ContrOCC and ERIC Databases within Gloucestershire County Council)

6.5 What support & training is available for families and carers?

The Gloucestershire Health and Social care are committed to working with service users' families / carers in a co-productive way to help ensure that care and support is person-centred. Full recognition of the value of families and unpaid carers' contribution and the need to provide training and support to ensure that they are able to continue their caring role is vital. This is particularly relevant for supporting young people and their families/ carers through transition and exploring all of the options that may be available to them.

Carers can also access the Positive Training Programme via Gloucestershire Carers Hub. The aim is to make training more accessible for Carers. Gloucestershire Health and Care NHS Foundation Trust also have Dementia specific training for Carers. We are beginning to map training that carers can access.

It has been identified as part of the workforce development that further training is required on

Early Intervention, Health and Wellbeing

- Eating well
- Health inequalities and reasonable adjustments
- Positive Behaviour Support (PBS)
- Communication and dysphagia skills,
- Specific training for the combined diagnosis of autism and a learning disability
- Complex and frail (including the management of physical health)

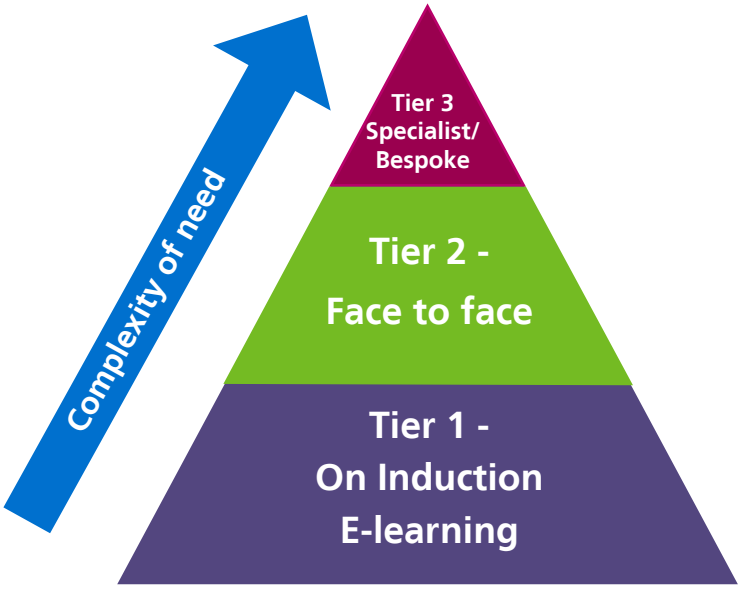
Risk, legislation and Safeguarding

- Use of mental capacity and the new liberty safeguards
- accessible information

Person-centred approaches

- Learning disability and autism awareness
- Making every contact count
- Support young people with learning disability and/or Autism transitioning to adulthood or those leaving the family home for the first time
- Supporting older people with a learning disability

A tiered approach to training is being considered by commissioners and for certain clinical pathways it is being trialled during 2018-2019 as part of the skills for care learning disabilities competency framework.



The Positive Behavioural Support Service is based within Gloucestershire County Council. It focuses on early intervention and prevention for adults. It ensures a cohesive multi-agency preventative approach is taken to prevent reliance on specialist services. It also enables adults with the potential to exhibit challenging behaviour to develop patterns and conditions for everyday living. The service works flexibly around individual needs meaning that they are able to work at any time of day, across weekends and bank holidays. In 2019 a review is being carried out and initial data (Chart 1 - Control group - did not receive PBS intervention and Chart 2 - Those who received PBS Intervention) looks promising. Additional benefits of the interventions include:

- Findings from the review indicate that people receiving support engage/ **access their community more.**
- The review also found that the previous PBS service had a **positive impact on staff,** increasing their resilience and confidence.
- Potential that through training and awareness this approach could have a positive impact by reducing **carer breakdown** and delaying the use of increased packages of care.
- Potential for **avoidable reduction in residential care** admissions.
- Potential for **avoidable hospital admissions** for individuals with environmental delirium whose behaviour changes as a consequence.
- Potential to **improve practice** - sharing of best practice more widely across disciplines including dementia, Acquired Brain Injury, autism and learning disabilities through the community of practice.

Chart 1 - Control group - did not receive PBS intervention

In the control group 100% saw an increase in their packages of care during 2019 (costs doubled).

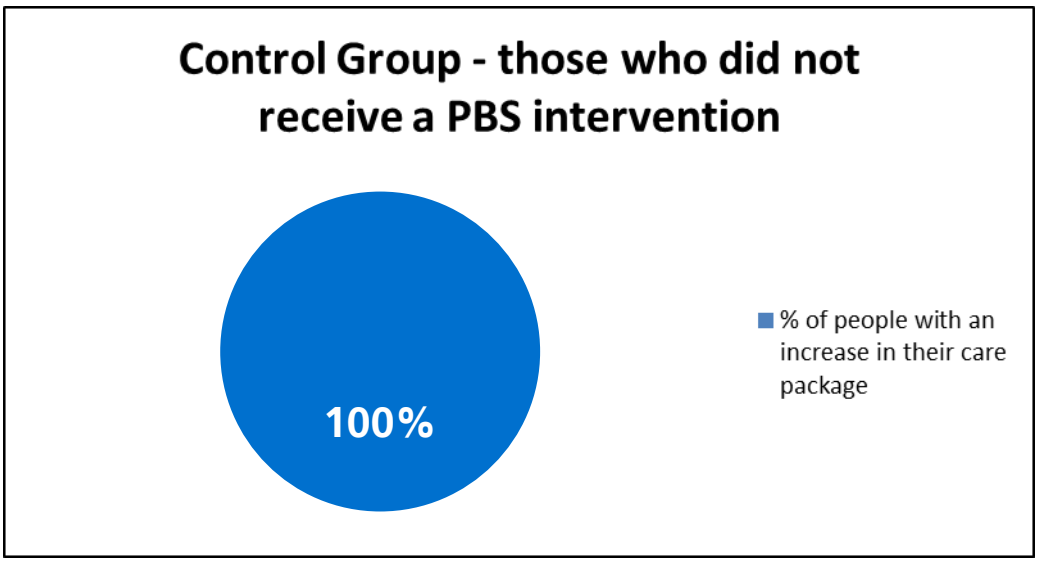
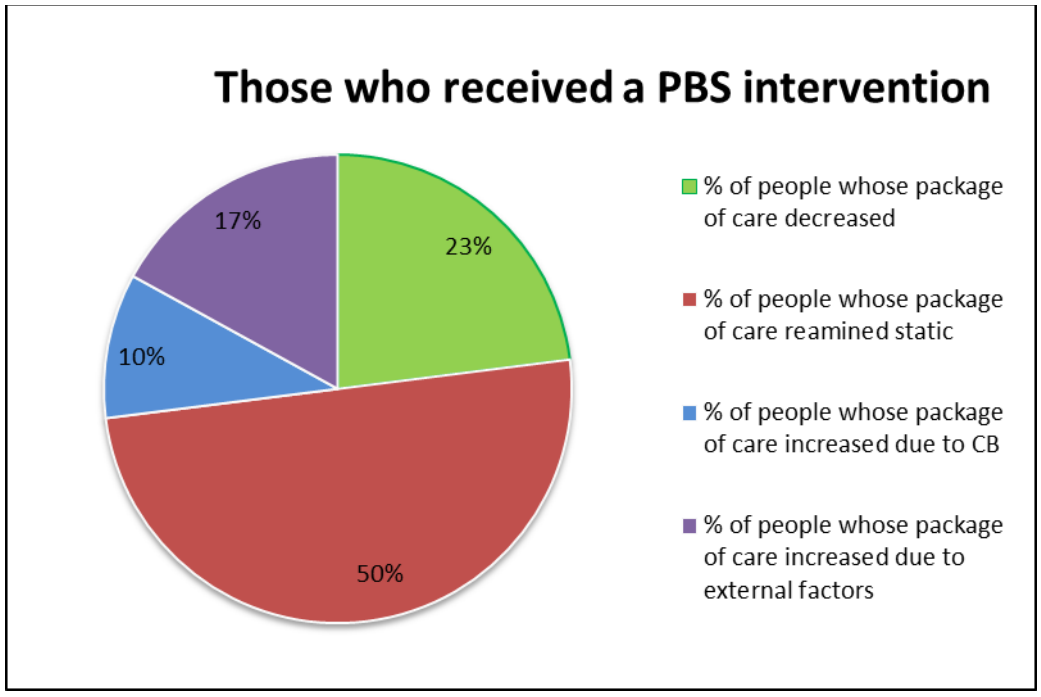


Chart 2 - Those who received PBS Intervention

In the group receiving the PBS intervention only 10% saw an increase due to behaviours that challenge services.



6.6 What does the health & social care workforce in Gloucestershire look like? Are there any gaps?

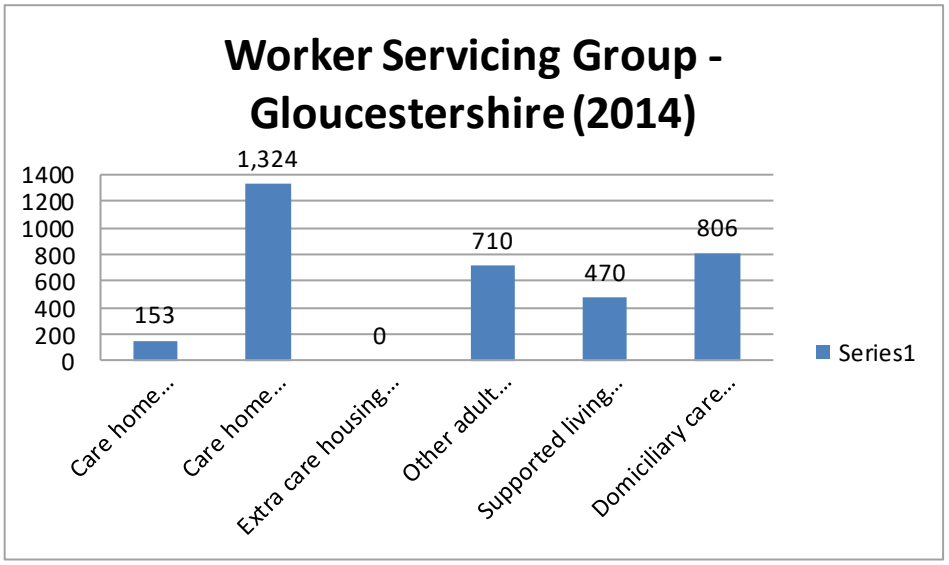
Our key challenge is to further develop our future workforce projections, to anticipate the roles and skill mix we will need in the future and to support our financial gap. We are working closely with the new care models programme and the pilots within our One Gloucestershire Integrated Care System (ICS) to understand how we need to adapt our current projections to meet these needs.

Workforce supply is known to vary by district across the county. There are areas of the county where we struggle to recruit carers – particularly in the North Cotswolds. This often depends on specific job roles. There is also recognition that, in a changing environment, with increasing requirements to meet ever more complex needs being managing in the community, (including frailty, dementia and challenging behaviour) the skills and expertise of some of the general social care workforce will need further development.

Care workforce data[1] from 2014 indicates factors which may potentially destabilise the labour market; in particular, an ageing workforce and a significant reliance on EU nationals.

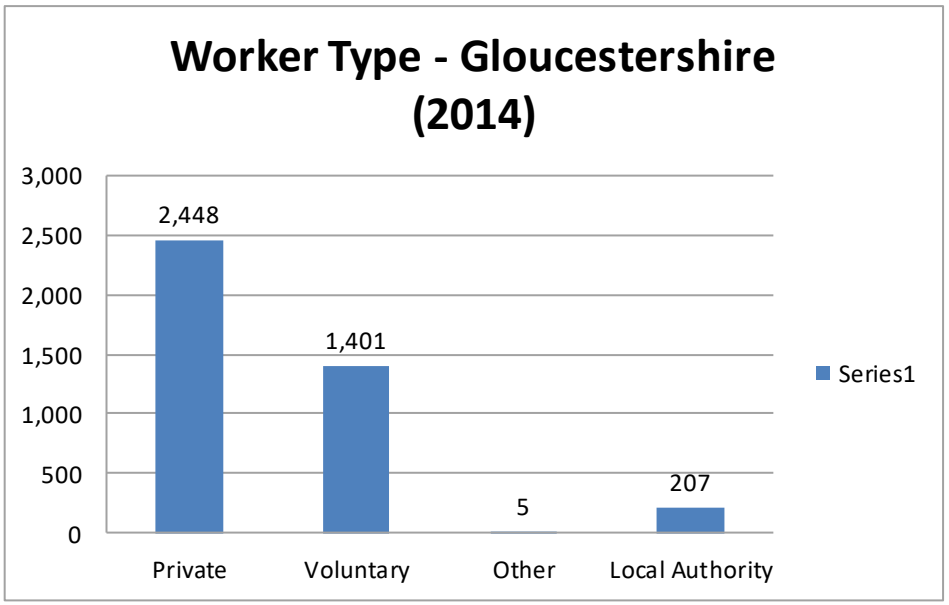
[1] https://www.skillsforcare.org.uk/NMDS-SC-intelligence/NMDS-SC/Adult-Social-Care-Workforce-Data-Set.aspx

Chart 3 - Worker Servicing Group - Gloucestershire (2014)



(SOURCE: Skills for Care Workforce Data set)

Chart 4 - Worker Type - Gloucestershire (2014)



Overview of the learning disability and autism spectrum disorders (LDA) workforce in Gloucestershire, 2017

(Source: Adult Social Care Sector and Workforce in Gloucestershire Report April 2018)

- There are around 5,900 jobs in LDA services in Gloucestershire within the local authority and CQC independent sectors.
- The vacancy rate is 6.7% and turnover rate is 32.7%.
- The average age of the workforce is 40.7 years old.
- Average hourly pay for direct care workers is £8.19.

83%

- **Of workers are permanently employed**

64%

- **Of workers have zero days sickness**

13%

- **Of workers hold an EU (non-British) nationality**

24%

- **Of all LDA jobs are held by men**

There are around 5,900 jobs in Gloucestershire within the local authority and CQC independent sectors. These jobs are spread across 200 establishments providing services to people with LDA needs.

Full-/Part-time status

Around 60% of those working in LDA services in Gloucestershire are employed on a full-time contract. A further 31% are part-time and 9% are on contracts with no fixed hours. The proportion employed full-time is higher than both the South West (54%) and England (53%) averages.

Zero-hours contracts

In Gloucestershire, approximately 19% of jobs within LDA services are zero-hours contracts. This proportion is the same in the South West on average, but is much higher (27%) in England. The proportion in Gloucestershire is not too dissimilar to other services, or across the adult social care sector as a whole.

Workforce ethnicity profile

In Gloucestershire, around 90% of jobs are held by individuals that identify as holding a white ethnicity. Of those with a BAME background, 5% identified as Black, African, Caribbean, or Black British. A slightly higher proportion of workers in the South West identified as white (94%), whilst the average in England was 82%.

Training

Care Certificate

Although the Care Certificate is available to all, the main target is workers who are new to social care. As a result, proportions of new social care workers engaged with the Care Certificate may be higher than the proportions given in the information below. The following information includes all job roles.

Around 27% of the LDA workforce in Gloucestershire has engaged with the Care Certificate – either completed or in progress/partially completed. This is lower than both the South West and England averages (both 31%).

6.7 Recommendations

- **Review of the workforce training gaps:** Utilising the Skills for Care Learning Disability and Autism competency framework.
- **Embed the recommendations from the training gaps review:** Including ensuring all training offers to care providers is accessible on a single point of access (Learnpro).
- Increase the uptake of the Care Certificate in the Learning Disabilities and Autism workforce.

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Learning Disability & Autism

#YourVoiceMatters

Learning Disability & Autism Strategic Needs Analysis

2018-2019

CHAPTER 7

What settings do people live in?

7. What settings do people live in?

7.1 Key Findings

80.8% of adult care users whose primary support need was learning disability felt as safe as they wanted

Market Position Statement

40% of the **103** people who answered the #YourVoiceMatters survey felt that they had a choice about where they live

The majority of people **(478)** with a learning disability and receiving support from social care live in 24 hour supported living accommodation.

People were positive about the help and support they received from the enablement team, but largely felt that demand for housing meant that they did not have a choice of location.

1 in every **3** people we spoke to felt they didn't feel safe in their homes

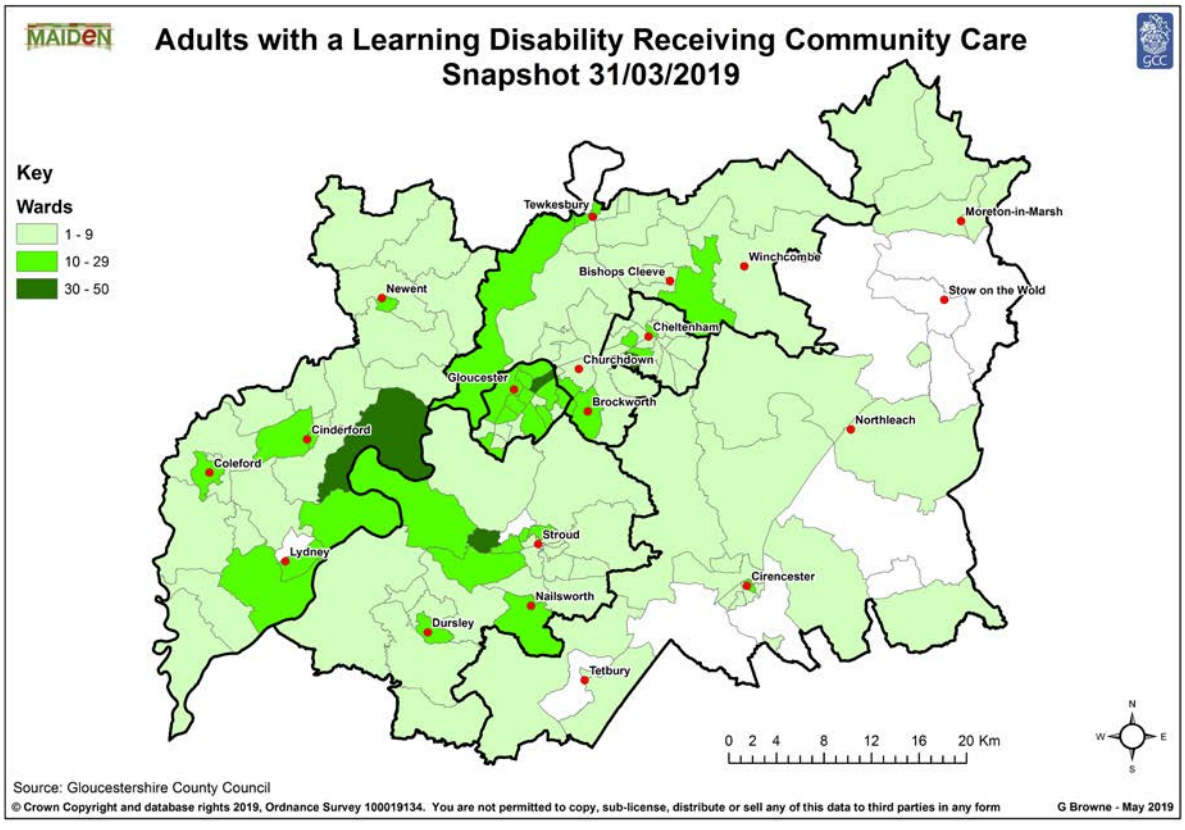


Figure 1 - Adults with a Learning Disability receiving Community Care Snapshot 31/03/2019

7.2 What settings do people live in?

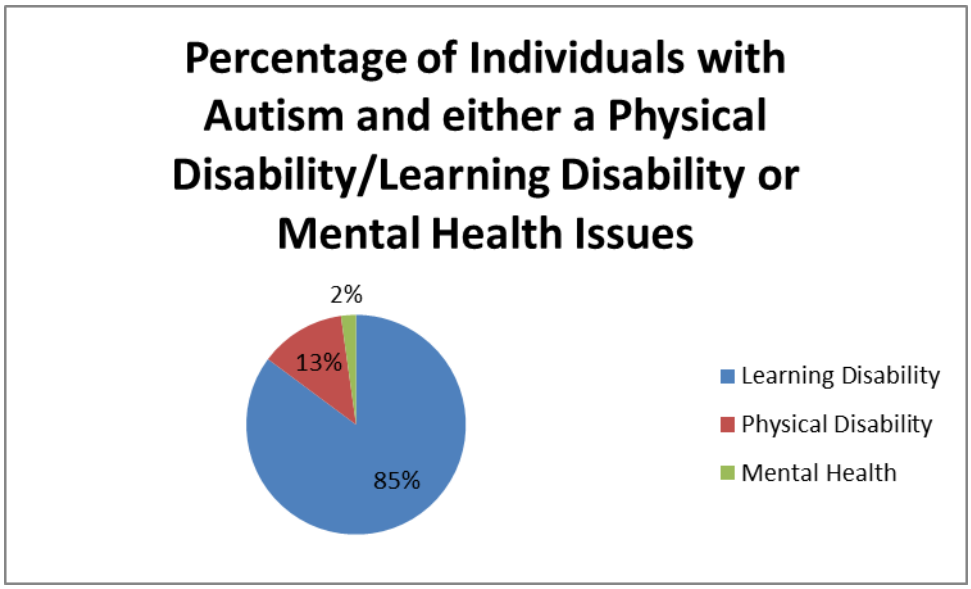
Table 1 – Individuals by Setting with a Learning Disability/Autism receiving a services from social care

Setting	Disability	Autism
Family home (domiciliary care)	21	10
Independent (on housing benefit)	305	136
Sheltered Accommodation	0	0
Extra Care Housing	10	0
Supported Living	235	74
Supported Living (24 Hour care)	478	150
Residential Care Home	341	136
Nursing Care Home	7	1
Short break	25	0
Supporting People	0	2

(Source: Controcc)

10 adults were receiving health care services but don't have comorbidities.

Chart 1 – Percentage of adults with Autism and either a Physical Disability/Learning Disability or Mental Health.



7.3 How are these settings spread around the county?

Table 2 - No. of adults with a Learning Disability by setting/District receiving a social care service

LD BY SETTING	Cheltenham	Cotswold	Forest of Dean	Gloucester	Stroud	Tewkesbury	Out of County Total
Community	36	20	51	95	65	39	
Community dom care	5	3	2	5	4	2	
Extra Care	3		4	2		1	
Nursing	2		1	2	1		
Residential	48	1	83	97	39	36	37
Shared lives					1		
Sheltered housing - dom care	1						
Sheltered housing / Supported living - dom care				1			
Sheltered housing -community	1		1				
Short break	2	1	7	6	3	4	
Supported living	36	23	62	42	48	15	9
Supported Living (24 hours)	60	27	105	127	98	61	0
Grand Total	**194**	**75**	**316**	**377**	**259**	**158**	**46**

Table 3 - No. of adults with Autism by Setting/District.

AUTISM	Cheltenham	Cotswold	Forest of Dean	Gloucester	Stroud	Tewkesbury	Out of County Total
Community	15	9	21	37	38	16	
Community dom care	4	2		2	1	1	
Nursing				1			
Residential	12		26	36	22	20	20
Supported living	11	5	20	15	17	4	2
Supported Living (24 hours)	13	9	38	39	30	21	
Supporting People	1				1		
Grand Total	**56**	**25**	**105**	**130**	**109**	**62**	**22**

7.4 How secure and safe do people feel?

As part of the engagement process people were asked the following questions:

- Do you like the place you live?
- Do you feel safe where you live?
- If you didn't feel safe, who would you tell?
- What might stop you from telling someone?
- Have you ever been treated badly or hurt because of your disability?
- Do you know where to get help if you don't feel safe?

Working in partnership with Victim Support, the Neighbourhood policing teams for each district, the specialist Ability policing team, and the Office of Police and Crime Commissioning, the **#YourVoiceMatters** engagement team were able to explore people's experiences of safety in and around their home.

One concern people had that was reported on a number of occasions was that they were often housed with ex-offenders who had recently transitioned out of halfway housing. They reported use of drugs in the shared houses and felt that the support staff were ill-equipped to deal with it. We asked if they had considered reporting the drug use anonymously to the police, but the individuals felt that their disabilities made it obvious that it was them who had reported the offender.

Professionals who work with people with additional care and support needs recognise these housing concerns, saying that ***"the most vulnerable clients have placements in unsafe locations"*** and reporting that people with family often have more positive experiences than people who are trying to navigate the health and social care system alone: ***"The people I support have had mixed experiences with feeling safe. Those without family can often have less choice over their placement due to lack of funding".***

We also discovered that people with additional needs often had an expectation of being treated poorly due to their disability. They often didn't recognise the abuse they received as a crime and had no expectation of a resolution: "***you just get used to it".***

However, in contrast, the data analysis from the 2017-2018 Adult Social Care Service User Survey 2017/18 suggest that nearly 80.8% of adult care users whose primary support need was learning disability felt as safe as they wanted. This proportion was much higher than that reported by those whose primary support reason was for other health/disability conditions (64.3%).

Overall, 1.8% of respondents whose primary support reason was learning disability felt less than adequately safe or not safe at all. The equivalent percentage was higher among those whose primary support need was for other health/disability conditions, at 6.7%.

7.5 Do people feel they have a choice?

40% of the 103 people who answered the **#YourVoiceMatters** survey felt that they had a choice about where they live and had help to find somewhere suitable for them. People were positive about the help and support they received from the enablement team, but largely felt that demand for housing meant that they did not have a choice of location:

> *"We provide an advocacy service to support adults with LD/autism to decide where they live. Sometimes, however, there are not many options for the person we support"*
>
> **- professional.**

7.6 Recommendations

• Strategic planning:

1. Ensure Housing with Care Strategy promotes the environmental needs of those with a learning disability and/or autism.
2. Recognise housing as part of the integrated social care system and develop sustainable housing options to support people with LD and Autism. This should include exploration of low sensory options within extra care.
3. Consideration of expanding the Shared Lives option.
4. Involve Occupational Therapists and people with LD and Autism in the development of new housing developments.
5. Ensure people can age well in their accommodation so they don't have to move, by forward planning in advance.
6. To influence providers to develop specialist homes to meet the changing needs of those with learning disabilities and autism, this should be via a clear Market position statement.
7. Work with District Councils to ensure the Home seekers website/ portal has clear indication of what adapted properties are available to those with disabilities.

• Social care assessment:

1. Ensure that the needs of people with LD and Autism are considered when housing placements are made.
2. Reducing out of county placements by working with local market providers to meet the needs of individuals through robust commissioning arrangements.
3. Ensure housing is reviewed as part of the three tier conversations.

• Performance and data:

Consideration of how data is recorded especially for autism. Further data and analysis planning for future.

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Learning Disability & Autism

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Learning Disability & Autism Strategic Needs Analysis

2018-2019

CHAPTER 8

How accessible are mainstream NHS Services?

8. How accessible are mainstream health & social care services?

8.1 Key Findings

75% of people we spoke to found it easy to see their GP.

29% of those age **18** or over predicted to have a learning disability (n3353 vs n11746) are known to primary care, this figure rises to 38% for those predicted to have ASD (n1850 vs n4918) known to primary care.

4 out of every **10** people we spoke to didn't know how to use their local community hospital.

67% of people we spoke to with a learning disability found it easy to have a hospital appointment.

29% of people with autism found it easy to have a hospital appointment.

The average number of admissions per month to acute care (Gloucestershire Hospitals NHS Foundation Trust) was **61** with the most common admission being for Pneumonia/influenza/ respiratory infection.

The average cost of care across the county per patient (based on the data held within SOLLIS data warehouse) was £1,682. Cheltenham average was considerably higher spend per learning disability population head at **£2,174.**

8.2 Do people find it easy to access their GP?

Most of the people we spoke to found it easy to see their doctor when they needed to. People told us about reasonable adjustments such as:

- Longer appointments
- An interpreter or chaperone
- Appointments before or after main surgery when it's quieter
- A separate waiting area
- Having time to absorb information before needing to act on it
- Easy-Read leaflets and information
- Appointments that fit around their bus pass or travel arrangements
- Annual Health Checks and
- Regular medication reviews.

Overall, people felt that their GP understood them, advocated for them and was trying to help them.

8.3 What are the main reasons people with LD and Autism are admitted to acute hospital?

> *My doctor knows my history, he knows what I'm talking about"-*
>
> **- adult with autism.**
>
> *My GP is fabulous and very supportive"*
>
> **- family carer.**
>
> *My GP advocated for paediatric referral for* **us"**
>
> **– family carer.**

Overall, people with a learning disability found it much easier to access appointments with required reasonable adjustments than people with autism without comorbid learning disabilities.

People with autistic spectrum conditions without learning disabilities reported difficulties with appointment times, sensory overload, and communication difficulties with the healthcare professional, difficulty communicating with the receptionist well enough to get an appointment, a lack of support to attend appointments and being passed back and forth between general medicine and mental health teams without coordinated care. This has led to a lack of confidence in the health services in the County within this group of people.

Additionally, people in the Forest of Dean have reported that they often can't attend the hospital appointments they are given as the bus timetable means they cannot get to the hospital by the time requested. Therefore, it could be sensible for a reasonable adjustment to include appointment times between 11am-3pm for those relying on public transport and free bus passes.

On a positive note, the people we spoke to who had come into contact with the learning disability liaison nurses were extremely positive about their experiences and said that it has made them much more confident and less frightened about going into hospital.

29% of those age 18 or over predicted to have a learning disability (n11746) are known to primary care, this figure rises to 38% for those predicted to have ASC (n4918) known to primary care.

There are currently only 35 children (under 14) on the GP LD Register compared with 1004 0-15 year olds with MLD, SLD or PMLD recorded as their primary need on their Education, Health and Care Plan.

The number of children on the LD register needs to increase to accurately reflect prevalence and to encourage families to request reasonable adjustments when attending appointments and ensure they are offered an annual health check when they turn 14.

Table 1 NUMBER OF CHILDREN WITH A LEARNING DISABILITY AGED (0-15)

Age Range	MLD	PMLD	SLD
Under 5	18	8	1
Aged 5 to 10	404	31	42
Aged 11-15	413	23	64
Total	**835**	**62**	**107**

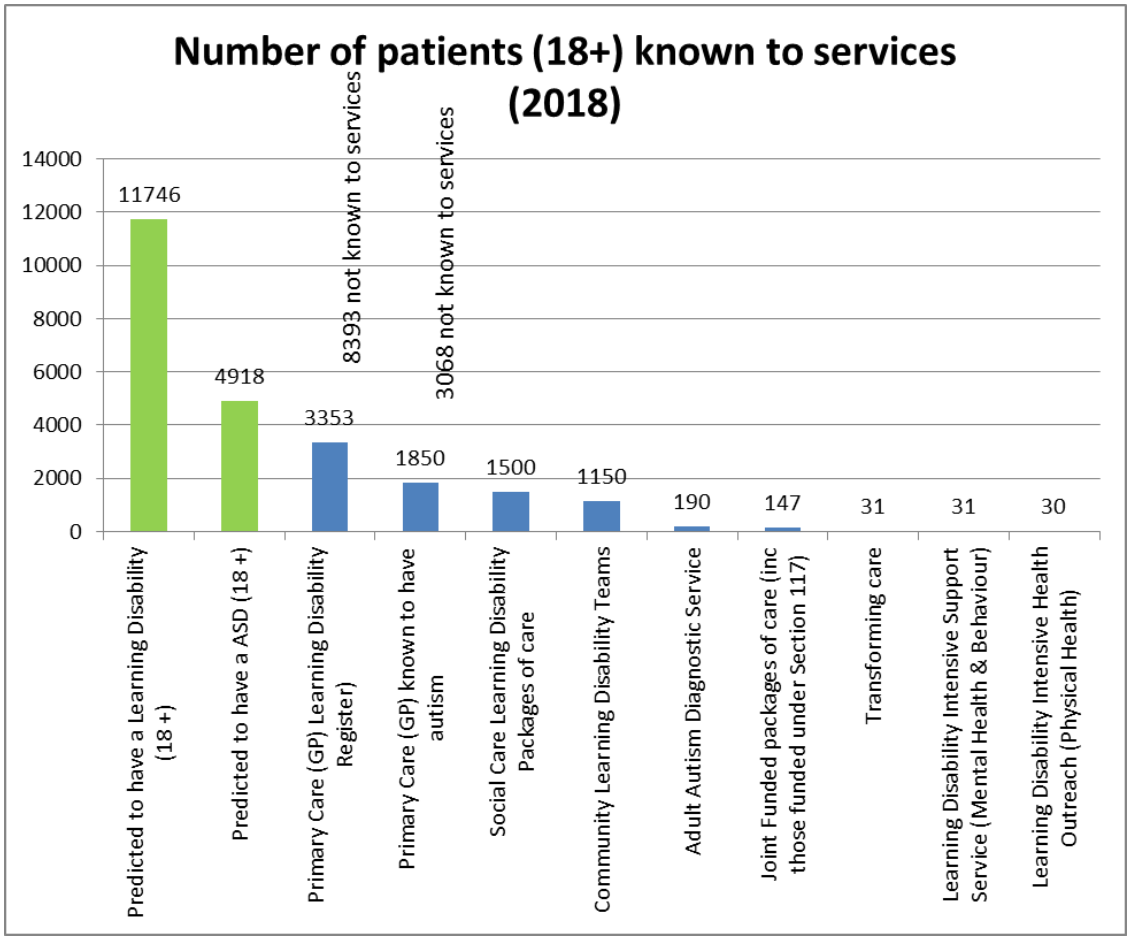
Table 2 NUMBER OF CHILDREN WITH A LEARNING DISABILITY AGED (0-25 BY LOCALITY)

Locality Area	MLD	PMLD	SLD
Cheltenham	210	11	21
Cotswold	114	6	22
Forest	149	12	30
Gloucester North	94	7	19
Gloucester South	185	17	40
Tewkesbury	159	11	20
Out of County	150	13	17
Total	**1061**	**77**	**169**

Table 3 CHILDREN REGISTERED WITH GP PRACTICES LD REGISTERS

Row Labels	LD Diagnosis <14	LD Diagnosis 14 -17 (eligible for annual health check)
Gloucester City	16	57
Stroud and Berkeley Vale	6	15
The Forest of Dean	8	40
Cheltenham	3	30
Tewkesbury Newent & Staunton	1	14
South Cotswolds	0	5
North Cotswolds	0	8
Grand Total	**34**	**169**

Chart 1 - Patients known to health services in Gloucestershire (by team) and compared to PANSI prediction.



The average cost of care across the county per patient (based on the data held within SOLLIS data warehouse) was £1,682. Cheltenham average was considerably higher spend per head within the learning disability population at £2,174.

Table 4 - Cost of care from November 2017 - September 2018 for learning disabilities patients.

District	Sum of Total Cost	Count of those with a learning disability	Average spend per patient
Gloucester	£1,857,320	1129	£1,645
Cheltenham	£1,084,726	499	£2,174
Forest of Dean	£1,015,611	618	£1,643
Stroud and Berkeley Vale	£1,010,257	687	£1,471
Tewkesbury	£227,428	147	£1,547
South Cotswolds	£150,982	102	£1,480
North Cotswolds	£141,797	81	£1,751
Grand Total	**£5,488,120**	**3263**	**£1,682**

Figure 1 - Geographical map of patients with a learning disability visits to their GP over 11 month period.

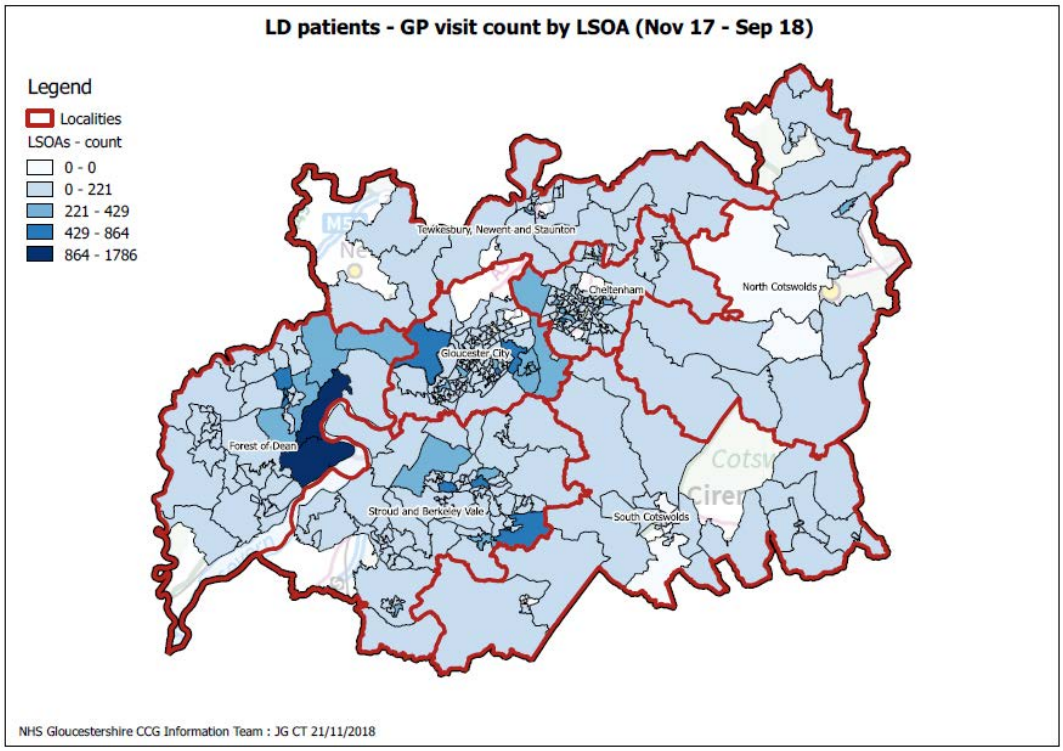
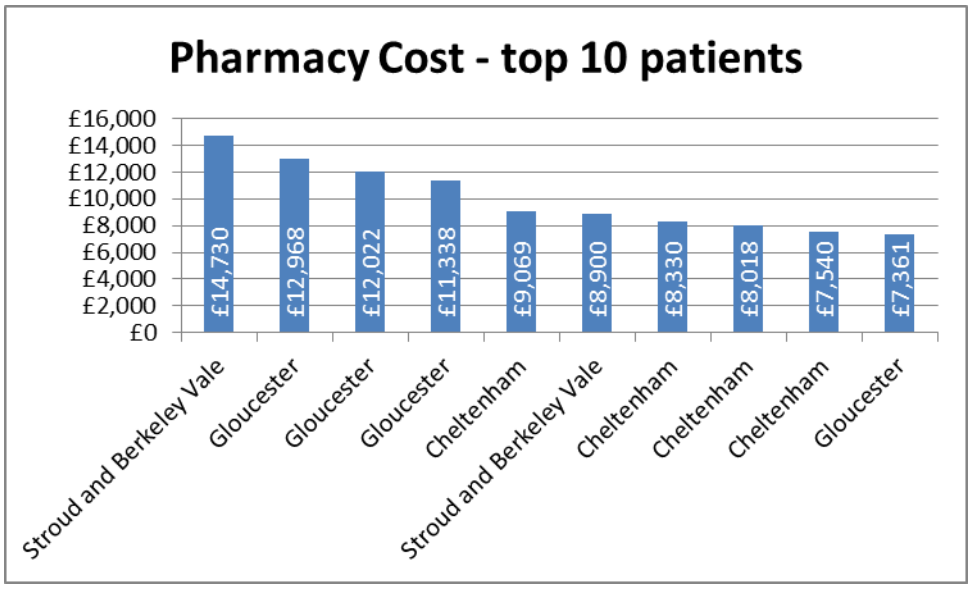


Table 5 - Analysis of pharmacy costs for those with a learning disability over 11 month period.

District	Sum of Pharmacy Cost
Gloucester	£387,130
Forest of Dean	£210,797
Cheltenham	£205,159
Stroud and Berkeley Vale	£164,699
North Cotswolds	£37,137
Tewkesbury	£25,351
South Cotswolds	£16,349
Grand Total	**£1,046,621**

Chart 2 - Analysis of 10 patients with the top pharmacy costs over 11 month period



From November 2017 to September 2018, £1,046,621 was spent on medications for those with a learning disability, the average spend was £321 per patient. Analysis of the data shows that ten patients' spend on medications was £100, 276, of these patients

- seven had received outpatient care (cost on average £336 during this period)
- nine had been to visit their GP 291 times (costing on average £1338 each for this period)
- five of the ten patients had been admitted to hospital under urgent care (costing on average each £119)

Table 6 - Admissions and re-admission data into Glos Hospitals NHS Foundation.

Total number of admissions (June 2017 – June 2018)	790
Number of individuals	387
Number of Individuals who had more than 1 admission	167

Table 7 - Highest number of admissions by GP Practice - top 6.

GP Practice	Number of admissions	Location
Rosebank Health	60	Gloucester
London Medical Practice	52	Gloucester
Aspen Medical Practice	47	Gloucester
The Portland Practice	40	Cheltenham
Gloucester City Health Centre	25	Gloucester
Yorkley Health Centre	25	Forest of Dean

Table 8 - Highest number of reasons for admissions - top 6.

Reason	Total Admissions
Pneumonia/influenza/respiratory infection	70
Epilepsy related	56
Pneumonitis	51
Dental/mouth	38
Chest/abdominal pain	26
Sepsis	22

Over the 11 month period (November 2017 to September 2018) the top reason for admissions to hospital for those with a learning disability was due to pneumonia/influenza type infection, this could potentially be avoided by increasing the uptake of the flu vaccination.

Table 9 - Total number of admissions per month.

Month	Total Admissions
June 2017	41
July 2017	54
August 2017	54
September 2017	52
October 2017	55
November 2017	78
December 2017	62
January 2018	63
February 2018	71
March 2018	68
April 2018	56
May 2018	73
June 2018	63
Total	790

The average cost for urgent care per patient with a learning disability was highest in Gloucester £293 compared to the lowest in Tewkesbury (£145), the hypothesis is that where there is community hospital in a locality the urgent care costs are lower than when there is only an acute district hospital (Gloucester and Cheltenham).

Table 10 - Cost of urgent care over 11 month period by locality.

District	Sum of Urgent Care Cost	Sum of Urgent Care Cost	Average cost per patient
Gloucester	£86,273	294	£293
Forest of Dean	£35,379	187	£189
Cheltenham	£32,630	117	£279
Stroud and Berkeley Vale	£30,142	158	£191
Tewkesbury	£4,793	33	£145
South Cotswolds	£4,598	23	£200
North Cotswolds	£3,608	23	£157
Grand Total	£197,423	835	£208

8.4 How well do we understand the reasons for prescriptions of antipsychotic drugs (AP drugs)?

The average prescription rate for AP drugs for those with a Learning Disability in Gloucestershire is 19.2%. The highest primary care cluster prescription rate is 27.2%.

Table 11 - People on Learning Disabilities Register on AP Drug.

Cluster	Patients with a Learning Disability (age 14+) on GP registers	Patients with a Learning Disability aged 14+ currently (ie. Within 3 months) on an AP drug (% based on patients with Learning Disabilities aged 14+)	% of LD register
Hadwen, Quedgeley and Rosebank	279	76	27.2%
Stroud Rural	185	49	26.5%
Aspen & Saintbridge	332	87	26.2%
North East Gloucester	93	23	24.7%
South East Gloucester	179	43	24.0%
Forest of Dean 1	601	138	23.0%
Tewkesbury, Newent and Staunton 1	224	44	19.6%
Inner City	171	29	17.0%
North Cotswolds 1	77	13	16.9%
Cheltenham 1	301	49	16.3%
Cheltenham 2	176	28	15.9%
Cheltenham 3	126	13	10.3%
Eastington/Frampton	137	13	9.5%
Berkeley Vale	159	15	9.4%
South Cotswolds	106	8	7.5%
Stroud Central	207	15	7.2%
Grand Total	**3353**	**643**	**19.2%**

There is little evidence currently to understand the rationale for antipsychotic drug prescribing for people with a learning disability or ASC from the data analysed. To resolve this, there are questions within the 2019/2020 Primary Care audit to understand the specific drugs and doses so that further work can be carried out to support the STOMP agenda.

8.5 How well are services meeting their requirements under the accessible information standards?

An audit carried out in 2018 by the County Council's Internal Audit department found that overall the council was performing 'Satisfactorily' when adhering to the NHS Accessible Information Standard. The report recognised the significant steps by the workforce in the Contact Centre and Adult Social Care to implement the standard and processes were largely working. At that time no formal complaints have been received by the Council, about the accessibility of information, since the standard was introduced. Commissioned providers are reviewed on the accessibility of information by contract monitoring processes. The recommendations that came from the Audit included ensuring a person's communication need continues to be recorded in the new Adult Social Care database, when this is implemented. It also advised that reporting on metrics surrounding the Accessible Information Standard is improved.

8.6 What demand do we expect from transitions?

Transition into adult services is a major life stage particularly for young people with learning disabilities and/or autism. It is essential that we guide young people and their families through this process. If individuals are supported as early as possible it can prevent the need for more specialist services in adulthood and enable the young people to reach their potential. Preparation for adulthood should happen as early as possible and individuals who may require support from adult services should be monitored from Year 9, when they are aged 13 or 14 years to ensure we can meet their needs.

Transition Strategy

In Gloucestershire we recognise that we need to work together to improve transition. Young people and their families have told us that this is a really difficult time and that they do not get the support they need. There is currently no agreed Transition Strategy in place outlining the formal transition processes and detailing how we will work in partnership to achieve the best outcomes for our young people as they enter adulthood. In 2020 we plan to work with our partners to develop and begin to implement a Transitions Strategy which will include:

- Identifying, communicating and accessing the young people who are likely to require support from adult services
- Planning for a smooth transition into adult services which may include gradually reducing packages within children's services to meet adult service levels
- Agreeing multi agency funding for young people between 18 and 25 who are continuing in education
- Escalation and early identification where the individual needs are complex and individual commissioning arrangements need to be put in place.

Panels

There are currently two panels in place to support children with additional needs. The Children and Young People's Multi Agency Resource panel (CYMAR) is a fortnightly meeting to discusses requests for funding residential placements. The panel consists of representatives from Commissioning, Placements, Education, Health and the 11+ Service.

The Personal Budgets and Exceptional Needs Group are led jointly by Health and Social Care Commissioners. Assessment information is brought to this panel and decisions are made on packages of care, along with Continuing Care eligibility. This panel and the decisions made will feed into transition planning for young people with complex health and social care needs.

As part of the development of the Transition Strategy the role of a Transitions Panel will be explored.

Preparing for Adulthood

Before a Child or Young Person becomes an adult, they should be supported to think about what they might want to do in adulthood. This can be anything from building friendships to finding a job or thinking about where to live in the future. The Ready, Steady, Go Transitions programme supports this approach and is widely used across health services within Gloucestershire to ensure young people are prepared for their transition to adult services. There is an Easy Read version available for children and young people with learning disabilities. We need to ensure Ready Steady Go documents are shared with all professionals working with our young people to ensure their needs are met.

Identifying and planning for young people

At present young people who are likely to require support as adults are not always identified and their needs communicated to adult services in a timely manner. This can result in a lack of planning for a smooth transition into adult services which can lead to crisis for individuals and their families and in some cases admission to hospital. This can be a particular issue for our most complex young people transferring back into Gloucestershire from residential school placements in other counties.

Disabled Children and Young People's Service

Currently around 480 children with disabilities are supported by the Disabled Children and Young People's service (DCYPS) within Gloucestershire County Council. A Transitions Lead has been appointed within DCYPS who holds an overview of the children and young people who will be transitioning into adult services. A monthly transitions meeting takes place with representatives from children and adults health, education and social care to plan for the young people moving to adult services.

Commissioners have been working with the Transitions Lead to understand the number of young people who will be transitioning into adult services from DCYPS. There are currently 88 children age 14 and above who are supported by the Disabled Children and Young People's Service. Professionals working with these young people were asked to predict whether or not the young people they work with will be eligible for support from adult service.

Table 12 - The breakdown of individuals by age.

Age	Total number of CYP
14	20
15	32
16	19
17	23

The needs of some of our complex children will be met in independent schools (including special schools) funded by GCC. In 2019/20 there were 12 children with learning disabilities and autism who were over 16 and attending independent schools. We can presume that these children are likely to require some level of additional support in adulthood and will need services to focus on ensuring a smooth transition out of children's services. The level of need of each of these young people will have to be assessed on an individual basis. It might be that they are not eligible for support from adult social care but will require support to find employment and access community services. If we can be proactive in putting this support in place it is likely to result in better outcomes for these young people and their families.

Table 13 - Numbers of Children with compex needs transitioning.

Primary Need	Number of children 5-11 years	Number of children 11-16 years	Number of children 16+ years	Total annual education cost
ASD	4	14	5	£880,000
MLD	0	13	2	£353,000
PMLD	4	1	2	£255,000
SLCN	1	9	1	£206,000
SLD	4	3	2	£235,000

Residential Placements

Our most complex children and young people with learning disabilities and autism may be in a residential placement. As of November 2019 there were 11 children and young people in 52 week residential placements costing a total of £47,000 a week, £2.4 million per year. It is likely that these young people will require support from adult services and their transition will need to be carefully managed. These are the young people who are most at risk at transition and who we really need to focus on working together to keep them in the community.

Table 14 - Residential Placements

CYP with ASD only	CYP with LD only	CYP with LD and ASD	Total
3	3	5	11

Some of these young people will be supported by DCYPS (Gloucestershire County Council) and also be in a residential placement or in independent schools so we need to be conscious of double counting.

There will also be children and young people in the county who are not receiving supported from DCYPS and are attending GCC Special School or are electively home educated. We need to ensure these children are not missed.

By working with the data we have on young people in independents schools, 52 week placements and supported by DCYPS we should be able work together across health, education and social care to prepare for the transition of our most complex children and young people.

Autism Transitions

One of the main priorities of the Autism Strategy is to improve transitions for young people into adult services. The first stage of this is to ensure that children and young people receive their diagnosis as soon as possible and the appropriate support and interventions are put in place.

The expected prevalence of children and young people is highlighted in the tables below, however without a full dataset across agencies it is difficult to provide the actual prevalence figures, to gauge if Gloucestershire is in line with expected prevalence.

Table 15 - Prevalence of ASD in children and young people.

Age	0-4	5-10	11-16	17-18	0-18
Number of children	34766	44019	40886	14875	134546
Expected number with ASD	417.2	660.3	490.6	74.4	1642.5
Expected number using average prevalence	417.2	528.2	490.6	178.5	1614.6

Our current figures indicate that 74 young people with ASD will be leaving children's services in 2019/2021. We do not know whether these young people will require support from adult services. The figures indicate that over half of the expected number of the current 17 and 18 year olds with autism have not been diagnosed in children's services using average prevalence. For the younger cohorts the expected number of children with ASD is closer to the average prevalence.

Home educated children with autism

The education data team report that as at January 2020, there are 49 pupils who are elected home educated, and 17 of these have ASD as the primary need (this is 34%), and we don't know if ASD is a secondary need of the other 32 children. They may need support from adult services.

Support in adult services for young people with a learning disability and complex medical needs.

For a small cohort of young people with complex medical problems and a learning disability there is no equivalent adult service for them to transition in to. This group is the first generation of individuals with learning disabilities and complex physical needs who are surviving into adulthood and current adult services are struggling to meet their complex needs. This is a recognised gap across the country.

Many of these young adults with learning disabilities and complex needs are in and out of hospital on a regular basis. For some their condition is deteriorating but for many they just have very complex medical needs. It is acknowledged that adult wards may not the best place for young people with complex needs and learning disabilities but there is currently no alternative process, team or service to support these young people.

These young people have come to be held within elderly care/palliative care/rehabilitation services in different areas across the country, where there is expertise in complex medical needs and also experience in controlling and managing symptoms and pain. Between 2012-2016, approximately 23 adults with a variety of complex neurodisabilities were seen by the Specialist Palliative Care team within Gloucestershire Hospitals NHSFT. This gap needs to be fully understood by commissioners.

Recommendations

Improve the experience of transition for young people with learning disabilities and/or autism and their families.

Develop a Transitions Strategy which will include:

- Identifying, communicating and accessing the young people who are likely to require support from adult services
- Planning for a smooth transition into adult services which may include gradually reducing packages within children's services to meet adult service levels
- Agreeing multi agency funding for young people between 18 and 25 who are continuing in education
- Escalation and early identification where the individual needs are complex and individual commissioning arrangements need to be put in place

Ensure Ready, Steady, Go is embedded within Health Services and shared with other professionals working with the young person.

Explore options for supporting young people in adult services with a learning disability and complex medical needs.

8.7 How effective is the diagnostic process and early support provided to children & families with a learning disability and/ or autism?

Autism

There is a national drive from NHS England to improve the timeliness of an autism diagnosis for children and young people and ensure that areas are focussing on pre diagnosis support and post diagnosis support. There is currently a recognised gap in post diagnostic support for families of children who have been diagnorsed with autism.

The NHS Long Term Plan states "Children and young people with suspected autism wait too long before being provided with a diagnostic assessment. A growing body of evidence supports the value of early diagnosis and treatment with evidence based interventions, which can significantly improve the quality of life of individual with autism and their parents or carers." Late diagnosis is associated with increased parental stress and delays early intervention. Studies indicate that interventions implemented early on are associated with significant gains in cognition, language and adaptive behaviour. Research has also linked the implementation of early intervention with improvements in daily living skills and social behaviour. It would appear that early diagnosis and intervention are imperative in the long term trajectories and quality of life for children with Autism.

Current Position in Gloucestershire

During 2019-2020 PALS and commissioners have received an increasing number of formal and informal complaints from parents and carers who are unhappy with the lengthy waiting times, lack of pre and post support and lack of a NICE compliant pathway, particularly for school aged children.

NICE compliance

NICE guidance state there should be a multi agency approach to diagnosis of ASC to make a robust diagnosis for children and protect individual clinicians from challenge.

Under 5s

The under 5s pathway is NICE compliant but not formally commissioned.

Age 5 – 11 years

For the 5-11 age group, referrals are made to the Community Paediatrics service, referrals are only accepted if there is a report from the school / Educational Psychologist / Advisory Specialist Teacher service. There is no multi-disciplinary team and therefore the pathway is not NICE compliant.

Age 11-18 years

GHC CYPS Clinic operates a specialist assessment and diagnosis service for neurodevelopmental disorders (ADHD, ASD alongside mental health co-morbidities) for children and young people over the age of 11 years. This service is not compliant with NICE guidelines. There is a psychiatrist and clinical psychologist who assess together therefore this at least provides some joint work which is more robust than one clinician. However, this could be improved through working with speech and language therapy and OT.

Timelines of Assessment:

Under 5s

Whilst the under 5's pathway is working, there is a growing waiting list. The current wait for the preschool clinic assessments in Cheltenham is 5 months, with 15 children waiting. The current wait for the preschool clinic assessments in Gloucester is 22 children which equates to a 7 month wait (Summer 2019 figures). There have been several complaints about the waiting time.

Age 5-11 years

The waiting time to the 5-11 years service is within the 18 week timescale. The service conducted an audit at the request of commissioners in July 2019.

Table 16 - GHC CYPS Referrals

GHC CYPS Neuro behavioural referrals received May-June 2018						
Accepted Referrals 46			**Total Referrals 42**			**Total Referrals**
Autism	ADHD	Both	Autism	ADHD	Both	88
21	20	5	25	13	4	

The referrals for query of autism are shown. In a 2 month period, 21 referrals for ASD were received.

Age 11-18 years

There is a waiting list for the Neuro clinic, which is around 12 months and before that time there is a wait for a choice appointment initially (this should be 4 weeks). Following a choice appointment the patient is listed for a Partnership appointment which can be a wait of around 7 months, however after the choice appointment, clinicians will often list a patient for a partnership appointment and the Neuro clinic so that waiting is minimised.

There is capacity to see 3 new cases per month, with 7 referrals per month received (according to a 2018 data report). In future, Gloucestershire clinicians would like to be able to offer timely assessment. As at January 2020, there are 17 young people waiting to be seen.

Pre diagnosis support

This is an important aspect to focus on, to ensure that children and young people are supported prior to diagnosis. It is recommended that current training (Autism Education Trust) provided by the specialist teacher service (Local Authority) continues and is increased to ensure schools have awareness of Autism. Also, it is recommended to continue advice and guidance provided by the specialist teacher service and continue to improve the Local Offer. A sub group will be led by the autism stakeholder group to bring together current parenting courses – Triple P, Webster Stratton to ensure there is a co-ordinated approach to courses and ensure that courses are tailored to parents.

Post diagnostic support

Currently there is very little commissioned post diagnostic support provided for CYP in County. Currently the ATS offer one half day session for parents of newly diagnosed children with autism. The same support is offered to all families regardless of how autism affects their young person. NICE guidance recommends appropriate post diagnostic support. NHSE are emphasising the importance of this within the Transforming Care agenda and this is likely to be an area picked up in any future CQC/Ofsted inspection.

CYP Learning disabilties with challenging behaviour

It is widely acknowledged that early intervention is key to reducing challenging behaviour and creating sustainable behaviour change.

An intensive Positive Behaviour Support service will be put in place in 2020 to work with a small number (around 14 CYP over 6 years) young people with learning disabilities and/or autism who are demonstrating challenging behaviours and are at risk of going into residential care. Placing these young people into residential care is expensive and is often not the best option for these young people and their families. Residential care also makes the transition to adult service difficult as often the reasons for the challenging behaviour have not been addressed and the behaviour becomes more ingrained over time. A residential school setting will "contain" these young people and provide a level of support that is not sustainable in adult services, following transition to adult services these young people often end up in crisis. By providing intensive support for families young people will have the opportunity to live a full life in their community rather than be sent to residential school.

8.8 Recommendations

Reasonable adjustments:

1. Reasonable adjustment to include appointment times between 11am-3pm for those relying on public transport and free bus passes travelling from outside of Gloucester or Cheltenham.
2. Increase the number of people known to primary care with a learning disability or autism. Target should at least be 1% of the population. Therefore, increasing the number of people who are being provided reasonable adjustments.
3. Increase the uptake of the Flu vaccination for those with a learning disability, autism and those that care for them to reduce the number of hospital admissions due to flu related reasons by 5% year on year.

CYP Autism Pathway

- The autism pathway should be NICE complaint for all age groups.
- Children and young people should receive a timely autism assessment and diagnosis.
- There should be adequate pre and post diagnostic support for families with children with possible ASC.
- Satisfaction of parents should increase as the autism pathway improves.

CYP with Learning Disabilities and Challenging Behaviour

- Implement intensive positive behaviour support service.
- Explore opportunities for increasing overnight short breaks.
- Work with adult services to develop a wider PBS service.

Transitions

1. Develop a transitions strategy to include:

- Identifying, communicating and accessing the young people who are likely to require support from adult services.
- Planning for a smooth transition into adult services which may include gradually reducing packages within children's services to meet adult service levels.
- Agreeing multi agency funding for young people between 18 and 25 who are continuing in education.
- Escalation and early identification where the individual needs are complex and individual commissioning arrangements need to be put in place.

2. Embed the Ready, Steady Go, Hello adapted toolkit to include those with learning disabilities and autism from age 14. Ensure consistent approach across all CLDT.
3. Forward plan with housing colleagues and ensure pipeline funding bids are claimed through NHS England to provide housing for our most complex children and young people.
4. Understand fully the cohort of patients with Learning Disabilities and Complex Medical needs who are now reaching adulthood. Ensure their needs are met in adult services.

STOMP-STAMP:

1. The ten highest prescribing patients to be actively case managed by the locality with support from 2Gether NHS Foundation Trust.
2. Further analysis on the prescriptions of antipsychotic medications (STOMP) between primary and secondary care (GHC – previously 2Gether NHS Foundation Trust).
3. Develop a joint programme of work between the top five prescribing primary care clusters, medications optimisation colleagues and specialist secondary care to reduce the % prescription rates to match the county average of 19.2%.
4. Development of standardised protocols for GPs and community pharmacists to support reduction of AP Drug prescription.

Equitable expenditure by localities:

1. Work with the Cheltenham locality (average spend per population head is £2174) to ensure equitable use of services to match the county average (£1682) to support health equality across this vulnerable patient group.
2. Work should be carried out using the clinical programme approach to ensure equity of expenditure for urgent care is similar across the county (Average county expenditure is £208 per patient).

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Learning Disability & Autism Strategic Needs Analysis

2018-2019

CHAPTER 9

What help and support is available to keep people out of trouble?

9. Help & support to keep people with LD & Autism out of trouble?

9.1 Key Findings

There are gaps identified in the provision of services for young people with borderline Learning Disabilities and/or ASC diagnosis.

58% of those open to Youth Justice on an active intervention were aged

16-17 years old.

42% were aged.

14-16 years old.

5% of those known to Criminal Justice Liaison Service have a learning disability.

4% have ASD.

There are limited care providers within Gloucestershire who can meet the needs of this population.

15 people are in secure forensic inpatient settings outside Gloucestershire.

9.2 What services are available to prevent antisocial or offending behaviour? Do they provide reasonable adjustments for people with a LD &/Or Autism?

"Forensic mental health services work with people who have mental health conditions and have committed a serious criminal offence, or are thought to be at high risk of committing an offence.

Forensic mental health services may care for people in secure hospitals or prisons. Most of the people who are in need of such services are thought to be a risk to both themselves and others.

Community forensic mental health services can also care for people out in the community following discharge from a secure hospital or prison. These community services may also be asked to review patients who are known to other mental health services, where there is a concern that someone may be at high risk of committing a criminal offence.

An important goal of forensic mental health is to treat any mental health problems that may have contributed to a pattern of criminal behaviour, and discharge a person back into the community with the right level of support when it is thought safe to do so."[1]

[1]A guide to mental health services in England-NHS Choices-Accessed 13/11/2017

Based on the national prison population, there are about 6,000 people with a learning disability in prison (Landman, 2016).

While National data should be applied with caution, it has been estimated that between 5% and 10% of those people known to community learning disability services have had contact with parts of the criminal justice system (Murphy, 2015).

Locally, this would equate to between 65 to 130 people.

There are 15 people (who are the commissioning responsibility of Gloucestershire) with learning disability and/or autism currently in secure forensic inpatient settings under Part Three of the Mental Health Act ("patients concerned in criminal proceedings or under sentence").

Table 1 Current commissioned forensic placements (noting this number will be reduced under the Transforming Care Programme by 2019/2020)

2018 Forensic Placements	LD (may include dual diagnosis of not ASD)	ASD only	LD & ASD
Low Secure (CCG)	1	0	0
Low Secure (Specialist Commissioning – NHS England)	5	0	4
Medium Secure (Specialist Commissioning – NHS England)	2	1	2
Non Secure (CCG)	0	1	1
Sub Total	8	1	6
Total		15	

There is a gap in local provision for young people typically with borderline learning disabilities and/or autism diagnosis, previous diagnosis of ADHD as a child, history or risk of offending. There is a need for support systems that change over time in response to changing needs so that more people with learning disability and/or autism who display behaviour that challenges, including those with a mental health condition and who are at risk of offending, so they are able to play a full part in society and have opportunities for inclusion in the mainstream.

9.3 Those that are in trouble?

Young People on an active intervention (Youth Conditional Cautions, Referral Order, Youth Rehabilitation Order, DTO Custody and DTO License) at 12 June 2018[2]. There were 38 Young People open to Youth Justice (snapshot):

- 16 Young People were recorded as having Special Educational Needs at their last assessment.
- 32 Young People were identified as having Speech/Language/Communication concerns.
- 58% were aged 16/17 years of age.
- 42% were aged 14/15 years of age[3].

A speech and language therapist is based with the Gloucestershire Youth Support Team to help train staff working with young people who have communication difficulties. This has been noted as an area of particularly good practice, and even won an award in 2019 for their work.

It is difficult to accurately estimate how many people with a learning disability and/or autism are involved in the various elements of the criminal justice system. This is due to a number of factors, including those people with a learning disability and/or autism who are not identified or recognised within the criminal justice system and an inconsistency in data collections and terminology (e.g. 'learning disability' and 'learning difficulty').

Table 2 - CLDT Caseloads known to police & courts[4]

Current individuals who had contact with police and courts			
Location	Police contact	Courts	Outcomes
Gloucester	22	9	1 in prison; 1 suspended sentence; 1 sectioned
Cheltenham	17	3	1 in prison
Forest of Dean	16	5	1
Stroud	8	5	6
CLDT			

Current Criminal Liaison Justice Service statistics

- 31 individuals who they support have a Learning Disability (5%).
- 45 individuals have speech and language difficulties (7%).
- 18 individuals have a diagnosis of Autism Spectrum Conditions (4%).
- 20 if these were open to CLDT, 11 were not.

[2] (Source: Gloucestershire Youth Support Team, Prospects Services).
[3] It is difficult to break down these figures by age as this would mean that many of the numbers would be less than 10 so due to Data Protection we would be unable to give you the exact figures.
[4] Data correct as of January 2018 – Source CLDT Audit of caseload.

There is currently no specific Learning Disability/ASC forensic service in Gloucestershire. The needs of individuals with a Learning Disability and/or Autism with forensic profiles are being met through existing Community Learning Disability Teams and The Criminal Justice Liaison Service (CJLS) with some support from the FIND team who are based in Bristol.

The CJLS provides interventions for persons from the age of 10, who find themselves within the criminal justice system, and are suspected of having health vulnerabilities such as mental health issues, a learning disability or substance misuse issues. The aim of the service is to help these people to access appropriate services provided by statutory and third sector organisations as quickly as possible.

The CJLS provides an assessment of needs and short term interventions, which are available for those who have been arrested and are in police custody, or charged with an offence and appearing in front of the courts. It aims to ensure that people with mental health problems or other vulnerabilities are diverted from the criminal justice system when it is appropriate, and to support them through the criminal justice system when the nature of the offence prevents diversion from occurring. However this occurs when then individual has had contact with the criminal justice system and does not focus on prevention and early support.

9.4 Recommendations

- **Identification and monitoring:**
  1. Specialist Health Services to identify and record those individuals who may have potential and actual forensic support needs within their system. This needs to be for both individuals with Learning Disabilities and individuals with Autism and needs the current RIO system to be adapted as required.
  2. Adult social care also needs to be able to identify and record those individuals who may have potential and actual forensic support needs. This needs to be for both individuals with Learning Disabilities and individuals with Autism.

- **Provider Market:**
  1. That commissioners, explore with local specialist providers the use of a full range of assessments/risk profiling, other than those currently available via the RIO system. That staff are trained in the use of these.
  2. Building on the current disabilities provider framework for commissioning support providers. This would involve commissioning a small number of highly skilled providers.

- **Strategic Commissioning:**
  1. Moving forward there would be benefit in exploring a step down service within Gloucestershire to return individuals to be nearer their local communities and to further rehabilitate them.
  2. Implementation of a Learning Disabilities and/or Autism Dynamic Support Register.

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2018-2019

GLOSSARY

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Word/Acronym	Meaning
ADASS	Association of Directors of Adult Social Services.
Advocate	An advocate is someone who is independent who can help your wishes to be heard.
AIM	Assisted Internship Model
Annual Health Check (AHC)	NHS GPs in England can be paid to undertake annual health checks for people registered with them who have learning disabilities and meet the eligibility criteria. They must be: • aged 14 and over • on the practice learning disability health checks register
AP	Anti psychotic.
Autistic Spectrum Condition (ASC)	Autism is a lifelong developmental disability that affects how people perceive the world and interact with others. Also referred to as Autism Spectrum Disorder (ASD).
Building Better Lives (BBL)	Gloucestershire County Council's policy to improve our services for people with disabilities through an all-age, all-disability approach.
BESD	Behavioural Emotional and Social Difficulties
Building the right support (BRS	NHS England policy for supporting people with Learning Disability and/or Autism.
Carer	A family member or friend providing unpaid care and/or support.
CASA	Community Advice and Support for Autism.
Census	A census is a complete population count for a given area or place taken on a specific date. The last government census was in 2011.
Chronic Heart Failure (CHF)	Heart failure is a complex clinical syndrome of symptoms and signs that suggest impairment of the heart as a pump supporting physiological circulation.
Children in Care (CIC)	A child in care is any child which has been in the care of the local authority for more than 24 hours.
Children's Social Care (CSC)	Services from the local authority which supports children and their families.
CIPOLD	Confidential Enquiry into Preventative Deaths of people with a Learning Disability.
Commission	To understand what is needed and to plan, purchase and evaluate services and support designed to meet those needs.

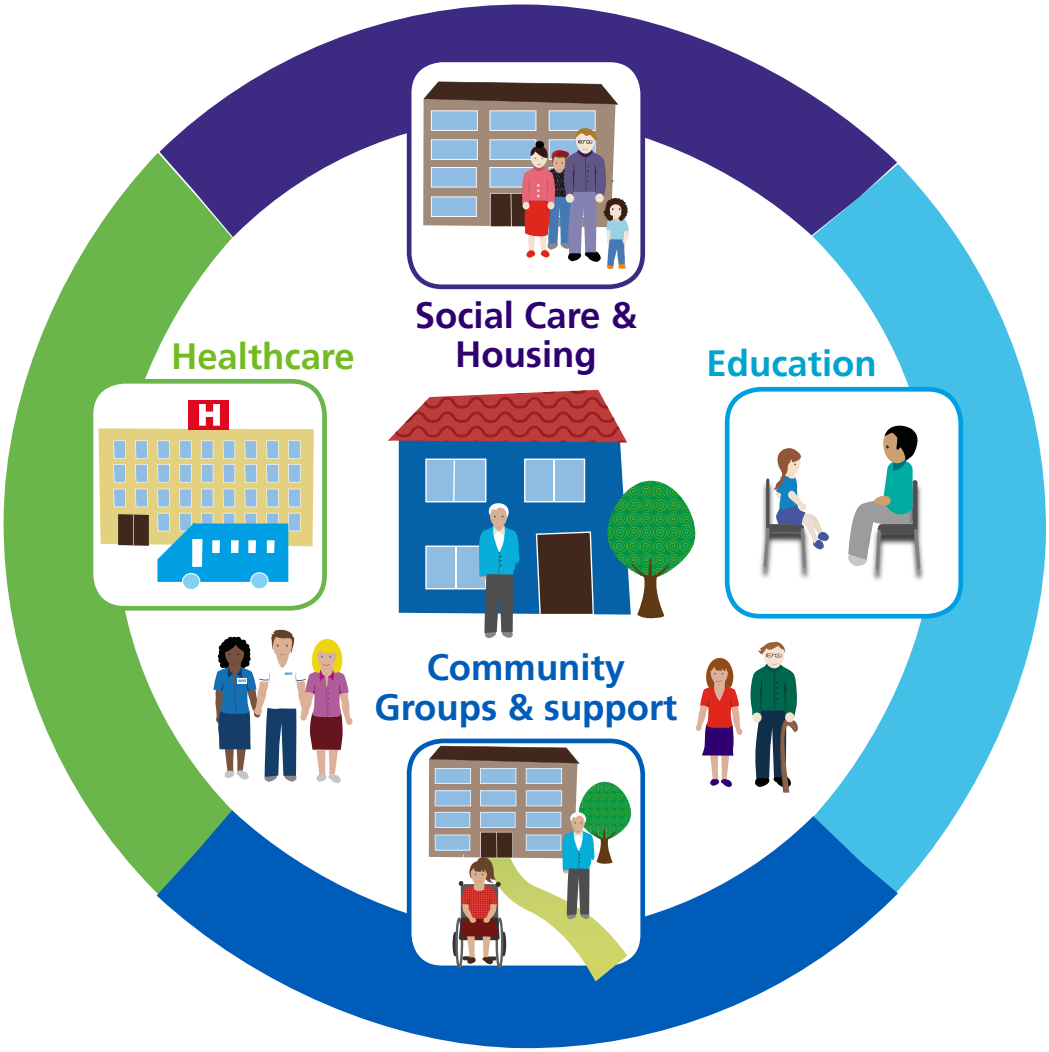
Congenital	An impairment present from birth.
Chronic Obstructive Pulmonary Disease (COPD)	Name for a group of lung conditions that cause breathing difficulties.
CQC	Care Quality Commission.
CYPS is now known as CAMHS	Child and Adolescent Mental Health Service Learning Disabilities Team.
Demand Management	Demand management is the process of changing demand for the council to do something by understanding what underlies that demand in the first place and identifying opportunities to reduce, remove or redirect that demand by influencing the behaviour of individuals or communities.
Demographic	A particular section of the population e.g. people with a Learning Disability.
Direct Payment	Money given by a local authority to someone with social care needs to organise and fund their support themselves.
Disability Living Allowance (DLA)	Money from the government if you have a disability to help fund mobility or care costs. This has been replaced by the Personal Independence Payment in the majority of cases.
DOLS	Deprivation of Liberty Safeguards.
DTO	Detention Training Order.
DWP	Department for Work and Pensions.
Education Health and Care Plans (EHCP)	An education, health and care (EHC) plan is for children and young people who need more support than is available through special educational needs support. EHC plans identify educational, health and social needs and set out the additional support to meet those needs.
Eligibility Criteria	The level of need someone must have to be considered for funding to provide support for that need.
ERIC	Gloucestershire County Council's Adult Social Care records database.
ESF	European Social Fund.
FIND	Forensic service for Intellectual and Neurodevelopment Disorders.
Forwards	Supported Employment Service for people with disabilities known to health and social care, SEN or NEET.

GEM	The Going the Extra Mile (GEM) Project is committed to help move people closer towards education, training, volunteering or work, including self-employment.
Gloucestershire Clinical Commissioning Group (NHS GCCG)	The organisation responsible for commissioning most services funded by the NHS in Gloucestershire. They replaced Primary Care Trusts (PCTs).
Gloucestershire County Council (GCC)	The local authority responsible for commissioning some public services in Gloucestershire including social care and public transport.
GP Profile	Data collected by GPs on health conditions.
GSAB	Gloucestershire Adults Safeguarding Board.
Hearing Impairment (HI)	Hearing impairment is a general term for a condition in which a person experiences a deterioration or loss of hearing.
ICS	Integrated Care System Plan.
IHAL	Improving Health and Lives.
Impairment	A health condition, injury, illness, or congenital condition that causes or is likely to cause a loss or difference of physical function or mental wellbeing.
Index of Multiple Deprivation (IMD)	A UK government qualitative study of deprived areas in English local councils.
JSNA	Joint Strategic Needs Analysis.
LDISS	Learning Disabilities Intensive Support Service.
LeDer	Learning Disabilities Mortality Review Programme.
LGA	Local Government Association.
Market	The range of providers that offer services / support. These can be from the private or third sector (including charities and community providers).
Methodology	A system of procedures used in carrying out research.
Moderate Learning Disability (MLD)	Moderate learning disabilities indicates an IQ = 35-49
Multi-sensory impairment (MSI)	Multi-sensory impairment means that a person experiences both sight and hearing impairments.
National driver	Legislation and/or policy which applies to the whole of England and with which Gloucestershire County Council must comply.
Needs analysis	A piece of research, which identifies and evaluates the needs of a target population (in this case people with a Learning Disability or Autism).

NEET	Not in Education, Employment or Training.
NICE	National Institute for Clinical Excellence.
(NOR)	Number on Register.
OFSTED	Office for Standards in Education.
Social, emotional and mental health (SEMH)	Social, emotional and mental health refers to an individual's needs and difficulties in managing their emotions and behaviour.
OT	Occupational Therapist
Other difficulty/ disorder (OTH)	A difficulty or disorder which is not covered by definitions of learning disability, specific learning difficulties, autism or sensory impairments.
Outcomes	An outcome is a meaningful and valued impact or change that occurs as a result of a particular activity or set of activities. There are three levels of outcomes: population outcomes (describe our aspiration for Gloucestershire as a whole); customer outcomes (describe the outcomes we want for a particular programme or service); and individual outcomes (describe how the individual service user, client or customer will be better off).
PALS	Patient Advice and Liaison Service.
Partnership Board	Members of the public, public sector, third and community sector organisations working together for joint solutions to common problems experienced by certain groups of people e.g. those with a Learning Disability.
PBS	Positive Behaviour Support.
PDD	Pervasive Development Disorder.
Personal Assistant (PA)	A support worker employed by people who need social care to enable them to live as independently as possible.
Personal Budget (PB)	An amount of money, determined by a person's needs, which is agreed by social services to fund support for an individual.
Personal Independence Payment (PIP)	Money from the government to help with some of the extra costs caused by a disability or long term ill-health. It has largely replaced the Disability Living Allowance.
PHE	Public Health England.
Physical Disability (PD)	A physical disability is a limitation on a person's physical functioning, mobility, dexterity or stamina.
Primary Care Clinical Audit Group (PCCAG)	A team within the Clinical Commissioning Group that analyse and audit information held by GP practices.

Projecting Adult Needs and Service Information system (PANSI)	National data on health conditions which may require social care support for those aged 16-64.
Projecting Older People Population Information System (POPPI)	National data on health conditions which may require social care support for those aged 65+.
Profound & Multiple Learning Difficulty (PMLD)	A profound and multiple learning disability (PMLD) is when a person has a severe learning disability and other disabilities that significantly affect their ability to communicate and be independent.
Projection	An estimate of a future situation based on the study of information that is currently available.
Scope	The extent of a study. What is and what is not investigated in the research.
Social, emotional and mental health (SEMH)	Social, emotional and mental health refers to an individual's needs and difficulties in managing their emotions and behaviour.
SEND	Special Educational Needs and Disability.
SEN support but no specialist assessment of type of need (NSA)	Where a child is identified as having Special Education Needs by an education setting but has not yet had an assessment from an external specialist e.g. Speech and Language Therapist.
Service User (SU)	A person who receives support from social services including financially.
Severe Learning Difficulty (SLD)	Severe learning disabilities indicates an IQ = 20-34.
Social housing	Housing provided by government agencies or non-profit organisations.
Speech, Language and Communication Needs (SLCN)	Speech, language and communication needs describes where individuals find it difficult to listen, understand and communicate with others and may need additional support with these skills.
Specific Learning Difficulty (SPLD)	Specific Learning Difficulties affect the way information is learned and processed. They are neurological (rather than psychological), usually run in families and occur independently of intelligence.
STAMP	Supporting Treatment and Appropriate Medication in Paedriatrics.
Statement(ed)	Legal assessment of a child as having special educational needs. This is now largely replaced by Education, Health and Care Plans where they are deemed appropriate.

Stopping over medication of people with a learning disability, autism or both with psychotropic medicines (STOMP)	STOMP is a national project involving many different organisations which are helping to stop the over use of these medicines. STOMP is about helping people to stay well and have a good quality of life.
Support	Assistance. It may be provided by a carer or in the form of professional and financial help or through the use of equipment.
Trend	A direction in which something is developing or changing
Visual Impairment (VI)	Visual impairment.


Social Care &
Housing
Healthcare
Education
Community
Groups & support