LEARNING DISABILITY AND AUTISM IN BRADFORD

A Health Needs Assessment

Dr Andrew O'Shaughnessy
Consultant in Public Health
City of Bradford Metropolitan District Council
February 2019

CONTENTS

Section 1 - Introduction

Defining Learning Disability

Learning Disability (LD) is defined by The Department of Health as:

> *"A significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood"* [1].

Defining LD in a way which is useful and easy to understand can, however, be difficult, particularly as there can be some confusion in peoples' perception of these conditions and their presentation. In particular, children and young people may also have special educational needs and disabilities (SEND), which are often defined more broadly as "Learning Difficulties" in the Education sector. These difficulties include, for example, Dyslexia and Dyspraxia or Attention Deficit Hyperactivity Disorder (ADHD). This report concentrates on Learning Disabilities with Learning Difficulties only referred to where context demands this. Broadly speaking, the former refers to a global developmental delay, whereas the latter is used to refer to specific difficulties processing certain forms of information.

Diagnosing Learning Disability

LD is generally present from birth, however it may not be recognised and diagnosed until the person is some years into childhood [2]. People with LD generally tend to have shorter lifespans than those without, however lifespans in people with LD are increasing year on year and it is vital that we consider their transition from childhood and their health, safety and quality of life as adults.

Assessment criteria for children and adults with a learning disability has been previously established [2]. This criteria outlines that people with an **IQ ≤70** are considered to have a LD, with varying levels of severity (Mild, Moderate, Severe and Profound). However, there is a consensus amongst professionals that IQ should not be used in isolation to assess the degree of learning disability. Unfortunately, they do not consistently use the same categories, which can lead to confusion. The test used in the UK to measure IQ in adults is generally the Wechsler Adult Intelligence Scale 4th edition [3]. However, it has been argued this test is not based on a generally accepted theory or definition of intelligence [3].

Diagnosis should not be attributed without clear evidence of meeting diagnosis criteria, which essentially requires significant impairment of both intellectual and adaptive social functioning, and impairments acquired during childhood. For those where a diagnosis is less clear or those with more severe learning disabilities, then a

formal assessment (following the British Psychological Society procedures [4]) or clinical judgement of skilled clinicians can be undertaken.

<u>Formal Diagnostic Criteria</u>

The formal Diagnostic & Statistical Manual of Mental Health Disorders (DSM-V) definition of 'Intellectual Disability' refers to limited functioning in three areas:

- Social skills (e.g. communicating with others)
- Conceptual skills (e.g. reading and writing ability)
- Practical ability (e.g. clothing/bathing one's self)

This is broadly reflects the DoH 2001 definition. Table 1 below outlines the relationship between IQ and severity.

Table 1   Relationship Between IQ and Severity of Learning Disability

Severity Category	Approximate % Distribution of Cases by Severity	DSM-IV Criteria (severity levels were based only on IQ categories)	DSM-5 Criteria (severity classified on the basis of daily skills)
Mild	85%	Approximate IQ range 50–69	Can live independently with minimum levels of support.
Moderate	10%	Approximate IQ range 36–49	Independent living may be achieved with moderate levels of support, e.g. in group homes.
Severe	3.50%	Approximate IQ range 20–35	Requires daily assistance with self-care activities and safety supervision.
Profound	1.50%	IQ <20	Requires 24-hour care.

It is, however, important to recognise that these criteria fail to recognise an at risk 'borderline' group who have an IQ above 70, but have a learning disability. This group of people may not be able to access help from the NHS (unless diagnosed with the condition) as it is their social care needs that unify them [4].

What Causes a Learning Disability?

Learning disabilities arise from differences in brain structure and function and affect a person's ability to receive, store, process, retrieve or communicate information. While the specific nature of these brain-based disorders is still not well understood, considerable progress has been made in mapping some of the characteristic difficulties of LD to specific brain regions and structures [5].

Progress has also been made in understanding the interface between genetics and LD, with documentation of LD and related disorders occurring with considerable frequency within members of the same families (e.g., parents, siblings, aunts/uncles, cousins) [5].

Learning disabilities may also be a consequence of insults to the developing brain before or during birth, involving such factors as significant maternal illness or injury, drug or alcohol use during pregnancy, maternal malnutrition, low birth weight, oxygen deprivation and premature or prolonged labour. Postnatal events resulting in

LD might include traumatic injuries, severe nutritional deprivation or exposure to poisonous substances such as lead [5].

Learning disabilities are not caused by visual, hearing or motor disabilities, intellectual disabilities (formerly referred to as mental retardation), emotional disturbance, cultural factors, limited English proficiency, environmental or economic disadvantages, or inadequate instruction. However, there is a higher reported incidence of learning disabilities among people living in poverty, perhaps due to increased risk of exposure to poor nutrition, ingested and environmental toxins (e.g., lead, tobacco and alcohol) and other risk factors during early and critical stages of development [5].

Defining Autistic Spectrum Conditions

Autism occurs early in a person's development. Someone with autism can show marked difficulties with social communication, social interaction and social imagination. They may be preoccupied with a particular subject or interest. Autism is developmental in nature and is not a mental illnesses in itself. However, people with autism may have additional or related problems, which frequently include anxiety. These may be related to social factors associated with frustration or communication problems or to patterns of thought and behaviour that are focussed or literal in nature. Autism is known as a spectrum condition, both because of the range of difficulties that affect adults with autism, and the way that these present in different people. For example, Asperger syndrome is a form of autism. People with Asperger syndrome typically have fewer problems with speaking than others on the autism spectrum, but they do still have significant difficulties with communication that can be masked by their ability to speak fluently. They are also often of average or above average intelligence [6].

Autism is not in itself a LD, although many people with LD will also be autistic (See Section 2 - Epidemiology)

For the purposes of this report, where it is appropriate, separate sections on Autism will be added to inform those working with autistic people and those who commission and provide services for them.

Diagnosing Autism

It is not always easy to make an Autism diagnosis. There is no lab test for it, so doctors rely, in the case of children, on observing the behaviours of very young children and listening to the concerns of their parents (it is now generally recognised that parents are considerably skilled in detecting early abnormalities in their child's development). Parents are likely to raise these concerns with their health visitor or general practitioner. This should then trigger referral for a general developmental assessment, referred to as stage 1 within the NAPC. Most often this initial referral is made to a general and/or community paediatrician, although in some areas the referral may go direct to speech and language therapy. These cases should be routed to child health as the single entry point. The paediatrician is likely to be involved in taking the general developmental history, performing a physical

examination of the child and arranging appropriate medical investigations depending on clinical presentation. If at any stage of this initial assessment an ASD is suspected, then a more extensive, multidisciplinary multiagency assessment (MAA) is likely to be needed [7].

Diagnosis of Autism in adults should follow NICE Clinical Guideline 142 [8], with consideration for assessment in adults with one or more of the following:

- Persistent difficulties in social interaction
- Persistent difficulties in social communication
- Stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests,
  And one or more of the following:
- Problems in obtaining or sustaining employment or education
- Difficulties in initiating or sustaining social relationships
- Previous or current contact with mental health or learning disability services
- A history of a neurodevelopmental condition (including learning disabilities and attention deficit hyperactivity disorder) or mental disorder.

What Causes Autism?

Autism spectrum disorder has no single known cause. Given the complexity of the disorder, and the fact that symptoms and severity vary, there are probably many causes. Both genetics and environment may play a role.

A detailed UK analysis employing analysis of hospital episode statistics suggested considerable under-reporting of autism [9]

Behaviour That Challenges [10]

Some people with a learning disability display behaviour that challenges. 'Behaviour that challenges' is not a diagnosis and is used in this guideline to indicate that although such behaviour is a challenge to services, family members or carers, it may serve a purpose for the person with a learning disability (for example, by producing sensory stimulation, attracting attention, avoiding demands and communicating with other people). This behaviour often results from the interaction between personal and environmental factors and includes aggression, self-injury, stereotypic behaviour, withdrawal, and disruptive or destructive behaviour. It can also include violence, arson or sexual abuse, and may bring the person into contact with the criminal justice system.

It is relatively common for people with a learning disability to develop behaviour that challenges, and more common for people with more severe disability. Prevalence rates are around **5–15% in educational, health or social care services** for people with a learning disability. Rates are higher in teenagers and people in their early 20s, and in particular settings (for example, **30–40% in hospital settings**). People with a learning disability who also have communication difficulties, autism, sensory

impairments, sensory processing difficulties and physical or mental health problems (including dementia) may be more likely to develop behaviour that challenges.

The behaviour may appear in only certain environments, and the same behaviour may be considered challenging in some settings or cultures but not in others. It may be used by the person for reasons such as creating sensory stimulation, getting help or avoiding demands. Some care environments increase the likelihood of behaviour that challenges. This includes those with limited opportunities for social interaction and meaningful occupation, lack of choice and sensory input or excessive noise. It also includes care environments that are crowded, unresponsive or unpredictable, those characterised by neglect and abuse, and those where physical health needs and pain go unrecognised or are not managed.

Why Do A Health Needs Assessment?

As people with LD and Autism live longer, their health and social care needs and costs of caring for them across Bradford and Airedale can be expected to rise in tandem, and there is a pressing need for robust forward planning, both to design effective and efficient services, and to make fiscal allowances for the resources that will be required. There is also a need to raise the profile of LD and Autism and their consequences among both professionals and other members of the population.

The strategic approach to LD and Autism should be underpinned by robust needs assessment of our population, giving a clear understanding of the extent, nature and geography of LD and Autism across the District. This project is designed to provide detailed data to facilitate this understanding, supported by the insight and experience of key stakeholders and thorough review of published evidence on the epidemiology of LD and Autism and the clinical and cost-effectiveness of interventions that can help in its management. It is important to ascertain from the outset that this project will cross the boundaries between health and social care and that this will be reflected in its methodology.

This project is designed to integrate with and support existing LD and Autism workstreams across the District and in particular to support and underpin the implementation of relevant local strategies.

Background

In 2008 the Public Health Directorate at NHS Bradford and Airedale Primary Care Trust (PCT), now situated at Bradford Metropolitan District Council (BMDC), instituted a rolling programme of Health Needs Assessments (HNAs) covering areas of key health and social need. These HNAs are based on a locally designed model, which was approved at the then PCT Clinical Executive. The model is focused on commissioning and informing the commissioning process, with a view to facilitating service redesign and pathway development. Key stakeholders and partners are involved in the HNA process, both commissioners, providers and patent groups where appropriate. Robust evidence review and inclusion of health economics elements are a key feature and these inform recommendations and associated business cases. The HNAs are viewed as live documents and are updated and hosted on the Bradford Public Health Observatory. They sit underneath and inform the Joint Strategic Needs Assessment (JSNA) and it is intended that this will extend to the District's Joint Health and Wellbeing Strategy (JHWBS).

To date the following HNAs have been completed, with several in second iterations:
- Dementia
- Sexual Health
- Smoking
- Alcohol
- Cancer
- Falls
- Renal Health
- Eye Health
- Mental Health
- Children
- Cardiovascular Disease
- Obesity
- Diabetes
- Long-term Neurological Conditions
- Oral Health
- Tuberculosis

LD and Autism have been identified by partners in Bradford and Airedale as an area in need of a detailed Health Needs Assessment and the lifetime of the report will include introducing it into key strategic and commissioning structures and processes, and through to service redesign as indicated.

Health Needs Assessment

This piece of work is part of a programme of Health Needs Assessments (HNAs) undertaken by the Public Health team at Bradford Metropolitan District Council. The aim is to cover all major health areas, for example Sexual Health, Cardiovascular Disease, Diabetes and Mental Health. These HNAs are based on a new model derived from the "process" focused Joint Strategic Needs Assessment (JSNA) approach. This is a move away from the production of a single document which is updated after a number of years to a "live" model where the product is hosted on the Bradford Public Health Observatory and regularly updated

The HNAs are strategic in that they identify areas in need of development and attention, and make needs- based recommendations which are agreed by a sponsoring Partnership Board and generate a prioritised work programme which promotes equitable access to evidence-based services.

This HNA is not designed to be read from start to finish, rather sections are presented as discrete pieces of work that can be read and used individually, with signposts to other sections as required.

It is essential to understand that this HNA is a continuous piece of work and that additional sections will be added over time, as with the JSNA. It is not possible to cover all facets of LD in one snapshot while so many developments are taking place both locally and nationally, such an approach would date rapidly.

Health needs assessment (HNA) is classically defined as 'A systematic method of identifying unmet health and health care needs of a population and making changes to meet those unmet needs' [11]. HNA was initially thrown into the spotlight in 1989 by the National Health Service Review which, by separating purchasers and providers, identified population health care purchasing, and therefore health care needs assessment, as a distinct task. Specific reasons for the introduction of HNA included:
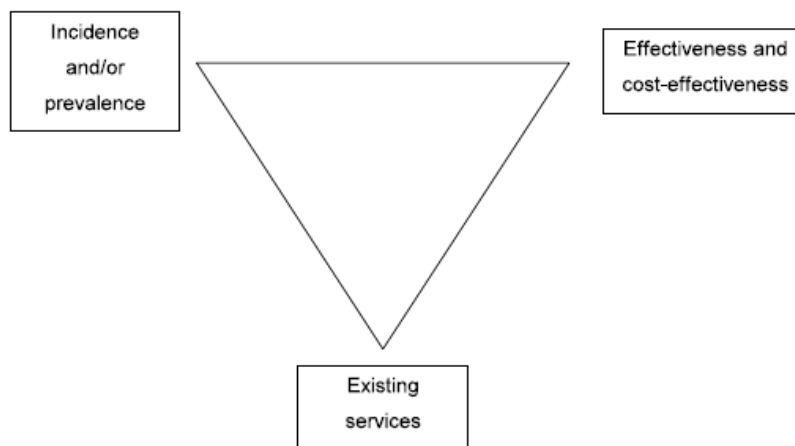
- Increasing costs of health care
- Constraints on public sector finance
- Doubts about effectiveness
- Health inequalities
- More explicit resource allocation

In a practical commissioning environment, HNA can be used to:
- Improve health and other service planning
- Set priorities
- Develop policies

Classically, HNA is based on the Stevens and Raftery model of the 'triangle of health needs assessment' [11] where the epidemiology of disease in a defined population is established and set against the nature and capacity of local services, with review of the clinical and cost-effectiveness of all available interventions used to inform planning to better match services with the disease epidemiology, need and demand

Figure 1 - The Elements of Health Needs Assessment

Two recognised HNA approaches will be used in this HNA:

1. Epidemiologically based HNA
This approach combines epidemiological approaches with assessment of the effectiveness and possibly the cost-effectiveness of the potential interventions.

2. Corporate HNA
This approach involves canvassing the needs and demands of professionals, patients, politicians and other interested parties. Usually, interviews are held using a structured or semi-structured format and the results analysed using qualitative methodologies such as those proposed by Mays and Pope [12, 13, 14].

There is a need to begin viewing HNA as a cyclical process rather than as a document encompassing identification of the relevant population, identification of issues and challenges, prioritisation of needs, action planning for change and finally a process for reviewing the cycle. This is the cornerstone of JSNA and pragmatically addresses issues around data becoming out of date and the danger that the HNA is viewed as purely a document on a shelf.

This piece of work is designed to act as a live toolkit, and it is anticipated that data will be updated on an ongoing basis and reviewed with close co-operation between Public Health, performance and other key partners. Equally, evidence and policy updates can be incorporated into the HNA as they are published.

Aims and Objectives

Aims
The aims of the Health Needs Assessment are as follows:
1. To help the health and social care economy understand LD and Autism
2. To inform strategic development and integrate with local strategies
3. To help direct commissioning towards achieving identified favourable outcomes
4. To provide a common source of information
5. To help and inform the Health and Wellbeing Board
6. To provide assurance that LD and Autism are being robustly addressed, informed by the best available evidence

Objectives
The principle objectives of this project are as follows:
1. To provide detailed epidemiological analyses
2. To review and report on relevant published evidence
3. To provide a firm policy framework at national, regional and local level
4. To make evidence-based recommendations
5. To maintain a framework of clinical and cost-effectiveness
6. To include social sciences research
7. To incorporate a nested qualitative study of key stakeholder opinions
8. An outcomes focus

Guidance Notes:
1. In respect of geographical footprint, the term 'Bradford' is used to describe the footprint of City of Bradford Metropolitan District Council. In addition, when data are presented relating to the three Bradford Clinical Commissioning Groups, this is made clear, and the term 'Bradford' is again used as an overarching term.
2. At the outset of this report it was requested by the TCB that both LD and Autism be considered. This has presented a number of challenges given that the two conditions have different evidence bases, data sources and regulatory frameworks. As such, there are a number of methodological points to note:
   a. Where intelligence, evidence or data are available separately for both LD and Autism, they are presented together in the same section of the report.
   b. Where intelligence, evidence or data are available for only one of the two conditions, this will be presented in the relevant section for that condition only.
   c. Where intelligence, evidence or data could be applied to both conditions, no distinction will be made within the relevant section.
3. One of the key observations seen when undertaking this piece of work is that the amount of policy, data, and evidence for Learning Disabilities significantly outweighs that for Autism. Consequently, there are many sections where only

Learning Disabilities can be covered. Autism sections are included alongside these when the relevant policy, data and evidence are available.
4. Strategic recommendations relating to each section are included at the section's end. In addition there is a global strategic recommendation set out below:

"It is recommended that Learning Disabilities and Autism be placed under a formal Programme, with a fully staffed Programme Office, placed at Waddiloves Health Centre, and run according to a formal Programme Management methodology, e.g. Managing Strategic Programmes"

REFERENCES:
1. Valuing People. A New Strategy for Learning Disability for the 21st Century. Department of Health. 2001.
2. Emerson, E. H., P. 2010. A working definition of learning disabilities. Department of Health: Improving Health and Lives: Learning Disability Observatory.
3. Webb, J., Psychologist, S.W.T.2012, Defining learning disability. eprints.hud.ac.uk
4. Sharpe R, Cohen R. Learning disability needs assessment – Cornwall Council. Updated 2017
5. The State of Learning Disabilities. National Center for Learning Disabilities. 3rd ed. 2014
6. Valuing People Now: Summary Report March 2009 - September 2010. Department of Health. Dec 2010.
7. Dover, C.J. & Le Couteur, A., 2007. How to diagnose autism. Archives of Disease in Childhood, 92(6), pp.540–545.
8. Clinical Guideline 142: Autism spectrum disorder in adults: diagnosis and management. National Institute for Health and Care Excellence. 2012.
9. Emerson E, Baines S. The Estimated Prevalence of Autism among Adults with Learning Disabilities in England. Department of Health 2010.
10. NICE Guideline 11: Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. National Institute for Health and Care Excellence. 2015.
11. Stevens A, Raftery J. Introduction Health care needs assessment., Vol 1, Oxford: Radcliffe Medical Press, 1994:1-30
12. Pope C, Mays N. Critical reflections on the rise of qualitative research. BMJ. 2009 Sep 15;339(sep15 2):b3425–5. 3.
13. Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. BMJ. 2000 Jan 8;320(7227):114–6. 13 4.
14. Pope C, Mays N. Qualitative Research: Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. BMJ. 1995 Jul 1;311(6996):42–5.

Section 2 - Epidemiology

Epidemiological analysis is usually the first part of health needs assessment and is followed by analysis of local services and review of guidance and literature in order to identify gaps and to inform commissioning strategies and plans that are based on the best available evidence. This section considers the key characteristics of the population of Bradford and Airedale that are important in determining current and future need for LD and Autism services in the context of the District as a whole. These include:

- Baseline age/sex profiles
- Population projections and trajectories
- Prevalence and incidence of LD and Autism
- Diagnosis rates

A key purpose of this report is to help commissioners develop commissioning plans for the management of LD and Autism in both Primary and Secondary care settings. It outlines the patterns of LD and Autism across the Bradford and Airedale District, with additional activity data supplementing population level statistics.

This section of the report draws on a number of data sources and describes the extent of LD and Autism in a number of categories:

- The overall burden of LD and Autism
- Changes in prevalence of LD Autism
- Diagnosed and undiagnosed LD and Autism
- Subtypes of LD and Autism

Please note: By necessity this report has accessed a wide range of epidemiological and demographic data sources. Where discrepancies in estimates of prevalence exist, these are due to the use of different data sources and should be interpreted in the context of the samples and methods used – please seek advice from the Department of Public Health if necessary. It should also be noted that in some cases data gaps have necessitated local statistical manipulation of figures to derive estimates.

Note: Key Definitions - Incidence and Prevalence

Incidence:
The term incidence can be used in a number of ways, however in the context of a health needs assessment, or indeed most epidemiological reports, it refers to 'the number of instances of illness commencing, or of persons becoming ill during a given period in a specified population' [1].

For example:

"Fifteen people were diagnosed with a LD in Bowling Ward between January 2012 and August 2013"

When most people use the term they actually mean the incidence rate, which differs slightly in that it is the rate at which events occur in a population [1] –

That is:

"New cases of LD occurred in Bowling Ward at a rate of ten per year between January 2012 and August 2013"

Prevalence:
Prevalence gives a figure for how many cases of a given condition there are in existence at a single point in time in a specified population. The important words are "at a single point in time" because prevalence can tell us only what is happening at a certain point. For example:

"As at December 1st 2012, there are seventy people with LD in Bowling Ward"

Gap between known and estimated numbers
As with any condition, there can broadly be thought to be two groups of people, those who **have been diagnosed** with the condition, and those who have the condition, but **have not yet been diagnosed** – for the purposes of this report this is referred to as the **Identification Deficit**.
In the case of LD and Autism, a number of key issues are relevant:
- The early and accurate diagnosis of LD and Autism is essential for optimal management. Early detection increases the likelihood of initiation of pharmacological and behavioural interventions, and the identification and management of any treatable signs and symptoms [2, 3].
- Those people who have LD and Autism but are undiagnosed may not therefore be receiving support and treatment. This threatens their quality of life
- The longer the duration between onset of symptoms and diagnosis, the poorer their response to eventual treatment and care is likely to be.

The epidemiology of LD and Autism will be dealt with in turn.

Epidemiology of Learning Disabilities

In this report, a distinction is made between "learning disabilities" and "learning difficulties." In the UK, the former refers to global developmental delay, whereas the latter is used to refer to specific difficulties processing certain forms of information. These difficulties include, for example, dyslexia and dyspraxia or attention deficit hyperactivity disorder (ADHD). From the onset of this report, the term "learning disabilities" is used, which is the prerogative term used in the UK to refer to people who have significant global developmental delay resulting in arrested or incomplete achievement of the "normal" milestones of human development [4]. This report does not address learning difficulties.

Case Definition

For the purposes of this report, the definition of LD used in the national strategy for LD, Valuing People [5] is used, i.e.:

A learning disability includes the presence of:
- *A significantly reduced ability to understand new or complex information or to learn new skills;*
- *A reduced ability to cope independently;*
- *An impairment that started before adulthood, with a lasting effect on development.*

This means that the person will find it harder to understand, learn and remember new things, and means that the person may have problems with a range of things such as communication, being aware of risks or managing everyday tasks.

Causes of Learning Disabilities

Learning disabilities are caused by something affecting the development of the brain. This may occur before birth (prenatally), during birth, or in early childhood up to age 18 years. Learning disabilities can be caused by any one of a variety of factors, or by a combination. Sometimes the specific cause is not known. Possible causes include the following [6]:
- An inherited condition, meaning that certain genes passed from the parents affected the brain development, for example Fragile X.
- Chromosome abnormalities such as Down's syndrome or Turner syndrome.
- Complications during birth resulting in a lack of oxygen to the brain.
- A very premature birth.
- Mother's illness during pregnancy.
- The mother drinking during pregnancy, for example Foetal Alcohol Syndrome.
- A debilitating illness or injury in childhood affecting brain development, for example a road traffic accident or child abuse.

- Contact with damaging material (like radiation).
- Neglect, and/or a lack of mental stimulation early in life.
- Some people with learning disabilities have additional physical disabilities and/or sensory impairments.

How Many People in Bradford have a Learning Disability?

In analysing the epidemiology of LD in Bradford we will first consider the *recorded* prevalence of LD, i.e. the number of people with LD who are identified on local registers and thus contribute to an aggregate total of cases.

There are three key data sources to consider:

1. GP Quality Outcome Framework (QoF) register
2. Children with LD known to schools
3. Social Care LD Team register (Adults 18+)

Table 1 below shows a summary report of data taken from these registers and will be referred to in the following discussion.

Table 1   Recorded Prevalence of Learning Disability, Bradford 2015-17

!ndicator	Period	Bradford		Yorkshire and Humber	England		
		Count	Value	Value	Value	Lowest	Highest
Children with <u>Moderate</u> Learning Difficulties known to schools per 1,000 pupils	2017	5,244	50.5	34.4	30	9.3	79.2
Children with <u>Severe</u> Learning Difficulties known to schools per 1,000 pupils	2017	433	4.17	3.79	3.73	0.62	8.07
Children with <u>Profound & Multiple</u> Learning Difficulty known to schools per 1,000 pupils	2017	240	2.31	1.35	1.27	0.26	4.06
Children with <u>Autism</u> known to schools per 1,000 pupils	2017	1,028	9.9	11	12.5	5	27.7
Children with learning disabilities known to schools per 1,000 pupils	2017	5,917	57	39.6	35	10.6	86.7
Adults (18+) with learning disability getting long term support from LAs per 1,000 pop.	2015/16	1,670	4.27	3.67	3.33	2.13	6.45
Learning disability: QOF prevalence	2016/17	3,607	0.60%	0.50%	0.50%	0.20%	0.80%

Source: Public Health England

1. <u>GP Quality Outcomes Framework (QOF) Register</u>

The QOF Register will tell us how many people with LD are known to **Medical Primary Care** services, i.e. General Practitioners (GPs). Table 1 shows us the most recent figures for Bradford and Airedale, Yorkshire and The Humber, and England. The most up to date figures show that, based on QoF data for 2016/17, there are **3,607** people **(of all ages)** on our QOF Register. This equates to **0.6%** of the population, a figure that is higher than the regional and national figures (note – this may reflect better case finding in Bradford and Airedale). It is important to acknowledge that these figures will also include Craven which is a constituent part of Airedale, Wharfedale and Craven CCG.

2. <u>Children with Learning Disabilities Known to Schools</u>

The latest figures for schools in Bradford and Airedale show that there are **5,917** children with LD known to our schools.

3. <u>Children with Autism Known to Schools</u>

The latest figures for schools in Bradford and Airedale show that there are **1,028** children with Autism known to our schools.

4. <u>Social Care Learning Disability Team Register (Adults 18+)</u>

The latest figures for the Social Care LD Team Register show that there are **1,670** adults aged 18+ who are in receipt of long-term social care support from CBMDC

Note - There may be significant overlap between the QOF figure and both other figures

True/Actual Prevalence Estimates

Next, we will consider the **True/Actual** prevalence of LD, i.e. the sum of people who appear on registers, plus those who do not and have not received a diagnosis/are unknown to services.

It is important to keep in mind that people with learning disabilities who are not known to specialist services may still have some significant support needs. For example, in a follow-up of the National Child Development Study cohort to age 33, people with mild learning disabilities were significantly more likely than their peers to be still living with their parents, be unemployed, have literacy and numeracy problems and to experience high levels of psychological distress [7].

> Note: - The current population estimation for England is **53,010,000**. With the population of Bradford and Airedale being **531,383** it is reasonable to take a **1/100th** figure from national estimates to give a pro rata estimate of local figures. Clearly this does not account for local demographic and epidemiological factors but remains a useful estimate for the purposes of this study.

To make an estimate of the true/actual prevalence of LD in Bradford we must consider a number of key academic studies with a view to applying them to Bradford:

1. An estimate of the true number of people with a learning disability is available [8], calculated by applying rates from an academic study [9] to the population aged 18 years and above. A study carried out in the North of England in 2014 used this approach to estimate the **diagnosis rate** for people with learning disabilities to be **23%** (1,313 registered patients out of an estimated total of 5,610 [10]). If we apply these figures to Bradford, we can estimate that there are **7,260 adults** with a LD across the District.

2. In **2004**, a research paper from the Institute for Health Research at Lancaster University estimated that, in England, there were [9]:

- **985,000** people with LD, of which:
  - o **796,000 were** aged 20 or more (448,000 men, 338,000 women) – of which:
    - ▪ **622,000** aged 20-59 (**365,000** men, **258,000** women)
    - ▪ **174,000** aged 60 or over (**94,000** men, **80,000** women)
- Of these, **224,000** were <u>known to social services</u>, of which:
  - o **169,000** were aged 20 or more (**93,000** men, **75,000** women) – of which:
    - ▪ **143,000** were aged 20-59 (**80,000** men, **63,000** women)
    - ▪ **26,000** were aged 60 or more (**14,000** men, **12,000** women)
- The remaining **761,000** people had mild to moderate learning disabilities and may not have been known to services.

The Lancaster University research also estimated that the total number of adults with a learning disability (aged **20 or over**) would increase by 14% from **796,000** to **908,000 by 2021**.
This paper is nearly 15 years old, however its findings are still pertinent and make an important contribution to this section.

3. A paper from the Centre for Disability Research published in 2008 looked at the numbers of people with learning disabilities **using social care services** [11]. This estimated that the number of adults with learning disabilities **known to services** in **2006/07 was 187,000** while those **using services** was **137,000**. Further, it estimates that in 2008 there were **147,000 using services**. The implication of the research is that more people with mild to moderate disabilities will become known to, and start using, services. Thus, the numbers of people using services is set to increase by more than 50% by **2018 to 223,000**.

The 'Identification Deficit' in Bradford – is a high or low gap preferable?

It can be useful to set the recorded numbers of people with LD and Autism against the estimates of true prevalence, in order to provide us with an estimated 'Identification Deficit', i.e. the number of people with LD and Autism who are not on a register and are thus, presumably, not accessing care services. These being, for Bradford in Table 2 below:

Table 2

<table>
<tr><td colspan="2" align="center"><u>Children with Autism</u></td></tr>
<tr><td>Children with Autism known to Schools</td><td align="center">1,028</td></tr>
<tr><td>Estimated True Prevalence of Autism (Children)</td><td align="center">2,310</td></tr>
<tr><td align="center">Identification Deficit</td><td align="center">1,282</td></tr>
</table>

<table>
<tr><td colspan="2" align="center"><u>Adults with Autism</u></td></tr>
<tr><td>Estimated Adults on Autism QOF</td><td align="center">3,000</td></tr>
<tr><td>Estimated True Prevalence of Autism (Adults)</td><td align="center">4,130</td></tr>
<tr><td align="center">Identification Deficit</td><td align="center">1,130</td></tr>
</table>

<table>
<tr><td colspan="2" align="center"><u>Children with LD</u></td></tr>
<tr><td>Children with LD known to Schools</td><td align="center">5,917</td></tr>
<tr><td>Estimated True Prevalence of LD (Children 0-18)</td><td align="center">3,551</td></tr>
<tr><td align="center">Identification Deficit</td><td align="center">-2,366</td></tr>
</table>

<table>
<tr><td colspan="2" align="center"><u>Adults with LD</u></td></tr>
<tr><td>Social Care LD Team Register (Adults 18+)</td><td align="center">1,519</td></tr>
<tr><td>Estimated True Prevalence of LD (Adults 18+)</td><td align="center">7,260</td></tr>
<tr><td align="center">Identification Deficit</td><td align="center">5,741</td></tr>
</table>

It is well recognised that the number of people with LD who do not access services is significantly higher than those who do, and mainly consists of those with less severe forms of the condition [9]. A challenge for commissioners and providers of care is whether to see this as a good or a bad thing – i.e. should we be aiming to reduce the identification deficit or is it preferable to have more people who do not require care from hard pressed local services? Some people will undoubtedly wish to not access services and some will wish not to be 'labelled', but on the other hand there may be those who really do need care services but are not accessing them for a variety of reasons. It is important to bear in mind the Inverse Care Law [12] which tells us that those in greater need of access to health and social care services are less likely to be accessing them.

In the case of autism things are slightly different. In the case of children, Table 2 shows us that there is actually an identification *surfeit*, suggesting that the evidence may underestimate the true prevalence, or, more likely, the criteria used to diagnose autism in the evidence differ from those used in schools. In the case of adults with autism, there is a clear expressed need locally in Bradford, with regular requests for diagnosis, care and support.

Ultimately these issues must be considered in the appropriate forums locally in Bradford and a strategic approach agreed.

Temporal/Predicted Changes in Prevalence

Population demographics in England are changing, and the population of people with learning disabilities increased by 53% over the 35 year period 1960-95, which equals 1.2% per year. A further 11% increase was previously projected for the 10 year period 1998-2008. These changes are largely the result of improved socioeconomic conditions, intensive neonatal care, and increasing survival [13]. Tables 4 to 6 below, derived from work undertaken at Oxford University, give an overview of how numbers in England are predicted to rise to 2035.

Additionally, a 2010 paper from the Learning Disability Observatory estimates future need for social care among adults with LD in England [14], key points being:

- All scenarios suggested sustained growth in the need for social care services for adults with learning disabilities over the full time period, with estimated average annual increases varying from 1.2% to 5.1% (average 3.2%)
- Approximately 25% of new entrants to adult social care with learning disabilities will belong to minority ethnic communities
- Approximately one in three of new entrants will coming from a home in which the child is eligible for Free School Meals (nationally one in six children in this age range are eligible for Free School Meals)
- By 2030 the number of adults aged 70+ using social care services for people with learning disabilities will more than double.
- Changes in *demand* (as opposed to *need*) are likely to outstrip changes in need due to a variety of factors combining to reduce the capacity of informal support networks to provide care, networks that have primarily relied on the unpaid labour of women. These factors include:
  - Increases in lone parent families
  - Increasing rates of maternal employment
  - Increases in the percentage of older people with learning disabilities (whose parents are likely to have died or be very frail)
  - Changing expectations among families regarding the person's right to an independent life.

More detailed estimates are available from the author

Table 4   People aged 18-64 predicted to have a learning disability, by age, England 2020-2035

	2020	2025	2030	2035
People aged 18-24 predicted to have a learning disability	126,131	125,425	139,226	141,441
People aged 25-34 predicted to have a learning disability	193,563	190,629	181,509	187,559
People aged 35-44 predicted to have a learning disability	177,551	187,948	193,965	191,725
People aged 45-54 predicted to have a learning disability	175,474	165,924	168,936	179,382
People aged 55-64 predicted to have a learning disability	157,803	169,442	164,884	155,807
Total population aged 18-64 predicted to have a learning disability	**830,522**	**839,368**	**848,518**	**855,914**

Source: PANSI

Table 5   People aged 18-64 predicted to have a moderate or severe learning disability, and hence likely to be in receipt of services, by age, England 2020-2035

	2020	2025	2030	2035
People aged 18-24 predicted to have a moderate or severe learning disability	29,305	29,506	32,998	33,727
People aged 25-34 predicted to have a moderate or severe learning disability	41,588	40,973	39,011	40,283
People aged 35-44 predicted to have a moderate or severe learning disability	44,625	47,295	48,859	48,381
People aged 45-54 predicted to have a moderate or severe learning disability	39,425	37,472	38,519	40,990
People aged 55-64 predicted to have a moderate or severe learning disability	34,343	36,614	35,431	33,481
Total population aged 18-64 predicted to have a moderate or severe learning	**189,286**	**191,859**	**194,818**	**196,861**

Source: PANSI

Table 6   People aged 18-64 predicted to have a severe learning disability, and hence likely to be in receipt of services, by age, projected to 2035

	2020	2025	2030	2035
People aged 18-24 predicted to have a severe learning disability	9,671	9,737	10,889	11,130
People aged 25-34 predicted to have a severe learning disability	11,641	11,453	10,907	11,293
People aged 35-44 predicted to have a severe learning disability	12,049	12,770	13,192	13,063
People aged 45-54 predicted to have a severe learning disability	8,708	8,284	8,562	9,095
People aged 55-64 predicted to have a severe learning disability	8,036	8,633	8,398	7,925
Total population aged 18-64 predicted to have a severe learning disability	**50,104**	**50,877**	**51,949**	**52,506**

Source: PANSI

Socioeconomic Factors

Prevalence of severe and profound learning disability is fairly uniformly distributed across the country and across socio-economic groups. Mild to moderate learning disability, however, has a link to poverty and rates are higher in deprived and urban areas [5]. The number of people with severe and profound learning disabilities in some areas is affected by past funding and placement practices, especially the presence of old long-stay patients and people placed outside their original area of residence by funding authorities.

A 2010 English study observed that [15]:

- Lower household socio-economic position was associated with increased rates of identification of intellectual and developmental disabilities especially less severe forms of intellectual disability.
- Higher area deprivation was independently associated with increased rates of identification of less severe forms of intellectual disability but decreased rates of identification of profound multiple intellectual disability.
- Minority ethnic status was, in general, associated with lower rates of identification of intellectual and developmental disabilities.

Ethnicity

The study above noted:
- Higher rates of identification of less severe forms of intellectual disability among Gypsy/Romany and Traveller children of Irish heritage, and higher rates of identification of more severe forms of intellectual disability among children of Pakistani and Bangladeshi heritage.
- Particularly high rates of Free School Meals eligibility among children of Traveller of Irish heritage (58%), Gypsy/Romany (42%), Bangladeshi (41%) and African (40%) heritage.
- Lower than average rates of FSM eligibility were observed among children of White British (12%), Chinese (10%) and Indian (10%) heritage.

Epidemiology of Autism Spectrum Disorders

An accurate epidemiological description of Autistic Spectrum Disorders (ASDs) is needed to inform public health policy and plan for education, housing and financial support services [17].

Case Definition

Classic Autism has gradually evolved into the concept of a larger "spectrum disorder" [18]. Autism Spectrum Disorder (ASD) is defined as a group of behaviours indicating social, communicative, and behavioural impairment or abnormalities. The essential features of ASD are [19]:

- Impaired reciprocal social interactions
- Delayed or unusual communication styles
- Restricted or repetitive behaviour patterns

Causes of Autism

ASD is highly heritable, but environmental factors are also implicated [20]. Multiple lines of evidence suggest the aetiology of ASD has prenatal origins. Onset of ASD symptoms typically occurs by age 3, although symptoms may not fully manifest until school age or later, and some research suggests symptoms can emerge between 6 and 18 months of age More severely affected children are more likely to be identified and reliably diagnosed at younger ages than milder cases

Incidence and Prevalence

Children

There are two key UK studies to consider:

1. **Taylor 2013 UK** [21] - a population study using the UK General Practice Research Database (GPRD) with annual autism prevalence rates estimated for children aged 8 years from 2004–2010 and annual incidence rates for children aged 2–8 years

- Annual prevalence rates for each year were steady at approximately **3.8/1,000 boys** and **0.8/1,000 girls**.

- Annual incidence rates each year were also steady at about **1.2/1,000 boys** and **0.2/1,000 girls**

2. **Baron-Cohen 2009 UK** [22] - a Special Educational Needs diagnosis survey in schools handed out to parents of all children aged 5–9 years. The mainstream primary school population was also screened for unknown cases.

- Prevalence estimates generated from the SEN register and diagnosis survey were **94 per 10,000** and **99 per 10,000** respectively.

- The ratio of known: unknown cases was estimated as **3:2, i.e. the true prevalence is estimated to be ~33% higher than the observed.**

- Taken together, the true prevalence was estimated to be **157 per 10,000**, including previously undiagnosed cases

<u>Adults</u>

Again, there are two key studies to consider:

3. Brugha 2011 [23] - A random sample from the Third National Survey of Psychiatric Morbidity in Adults in England in 2007.

- The weighted prevalence of ASD in adults was estimated to **be 9.8 per 1000**
- Prevalence was not related to the respondent's age.
- Rates were higher in:
    ◦ Men
    ◦ Those without educational qualifications
    ◦ Those living in rented social (government-financed) housing
    ◦ There was no evidence of increased use of services for mental health problems.

4. Brugha 2014 [24] - Clinical assessments of 7274 Adult Psychiatric Morbidity Survey participants combined with a population case-register survey of 290 adults with intellectual disability.

- The combined prevalence of autism in adults of all ages in England **was 11/1000**
- It was significantly higher in those with moderate to profound intellectual disability
- Male gender was a strong predictor of autism only in those with no or mild intellectual disability

Table 1 below shows *estimates* of these studies translated to the three Bradford CCGs. (Note there are confidence limits surrounding these estimates - please contact the author to discuss further)

Table 1 Estimates of ASD Prevalence in the three Bradford CCGs

			AWCCCG	BCCCG	BDCCG
Children	**Observed**	**Taylor 2013**	72	87	179
		Baron-Cohen 2009	304	363	752
	TRUE	**Baron-Cohen 2009**	494	592	1224

		AWCCCG	BCCCG	BDCCG
Adults	**Brugha 2011**	1215	873	2462
	Brugha 2016	992	712	2009

Temporal Changes in Prevalence

Following a fivefold increase in the annual incidence rates of autism during the 1990s in the UK, the incidence and prevalence rates in 8-year-old children reached a plateau in the early 2000s and remained steady through 2010 [21]. The rising prevalence of ASD diagnoses can be largely attributed to broader diagnostic criteria, adoption of dimensional assessment strategies, increased awareness, linking of services to diagnosis, and the inclusion of milder neurodevelopmental differences bordering on normality [18].

Socioeconomic Factors

- Recent European studies suggest that low socioeconomic status is associated with an increased risk of ASD [25].
- Prevalence of ASD with associated Intellectual Disability (ID) was higher in areas with the highest level of deprivation and the highest percentage of unemployed adults, persons with no diploma, immigrants and single-parent families.
- No association was found when using occupational class.
- Regarding ASD without associated ID, a higher prevalence was found in areas with the highest percentage of immigrants [25].
- The prevalence of ASD with associated ID and of severe isolated ID is more likely to be higher in areas with the highest level of deprivation [25].
- It has been proposed that clusters are linked to the education level of parents—those with a college education are more likely to obtain an autism diagnosis than those who did not graduate from high school [26].

A higher level of education could also be an indicator of being wealthier, and therefore having better access to resources such as better preventive medical care and paediatricians [10].

Ethnicity

- Studies conducted in North America indicate large racial/ethnic disparities in the diagnosis of ASDs [27].
- Others show that immigrant children have similar prevalence rates of ASDs as native children, although they are diagnosed later compared with native children.
- After analysing the results of studies conducted in Europe, it is unclear if higher prevalence estimates of ASDs among immigrants in this region reflect true differences, especially considering many potential confounding factors, e.g. genetic, biological, environmental and cultural.

Considering the number of people migrating within Europe there is a substantial need to study further the prevalence of ASDs in immigrant groups [27].

People with Both and LD and Autism

One of the key tasks of the Improving Health & Lives Learning Disabilities Observatory, commissioned by the Department of Health, is to support the National Autism Strategy by developing estimates of the prevalence of autism among adults with learning disabilities in England. This work is available as a key report published in 2010 [16].

Prevalence of Autism among Adults with Learning Disabilities

Key evidence proposes to employ two prevalence rates: a **lower estimate of 20%** (close to the median rate across studies) and an **upper estimate of 30%** (the higher rate reported by studies on community-based samples of adult **users of specialised learning disabilities services**) [16]. In Bradford this translates to a range of **1,452** to **2,178** if these rates are applied to the estimated *true prevalence* – it is important to note, however that the research can also be applied to the population of people in contact with services where the estimated range will be **334** to **501**.

The authors also estimate the prevalence of autism in children with LD the estimated percentage of children with learning disabilities who also have autism to be 30%, however complexities in these estimates make this figure unsuitable for general application to our population of children with LD.

Summary Tables and Figures

Table 2 below provides an overall summary of epidemiological and activity data.

Figure 1 provides a summary of key LD data

Figure 2 provides a summary of key Autism data

Table 3 Summary of Epidemiological and Activity Statistics, Bradford 2018

Scope	Year	Source/Methodology	Bradford	Bradford and Craven	AWC CCG	BCCCG	BDCCG	Strategic Context
Qof Prevalence of LD (All ages)	2017/18	eMBED QoF Figures		4,028	886	995	2,147	
All Age Prevalence of LD/1,000 pop.	2017/18	eMBED QoF Figures		6.37	5.57	7.09	6.45	
QoF Prevalence of Autismt (All Ages)	2017/18	eMBED QoF Figures		3,441	1,039	463	1,939	
All Age Prevalence of Autism/1,000 pop	2017/18	eMBED QoF Figures		5.44	6.53	3.3	5.82	
Social Care LD Team Register (Adults 18+)	2018	CBMDC Social Care	1,519					
Adults with LD geetting long term LA support (18+)	2015/16	Care Acitivity and Finance Report	1,670					
Children with LD known to Schools	2017	PHE	5,917					
Children with Autism known to Schools	2017	PHE	1,028					
Waddiloves Caseload	2018	Waddiloves	1,150					
Estimated True Prevalence of LD (Adults 18+)	2018	Germain & Williams 2014	7,260					
Estimated True Prevalence of LD (Children 0-18)	2014	Emerson 2014	3,551					
Estimated True Prevalence of LD with Behaviours that Challenge (Children 0-18)	2018	Emerson 2014	415					
Estimated True Prevalence of Autism (Adults)	2018	Brugha 2011, Brugha 2016		4,130	1,103	792	2,235	
Estimated True Prevalence of Autism (Children)	2018	Baron-Cohen 2009		2,310	494	592	1,224	
Estimated Prevalence of Adults with LD who also have Autism	2017/18	Emerson & Baines 2010	1,452 - 2,178					
Estimated Incidence of Autism (Children aged 2-8)	2013	Taylor 2013	1.21/1,000 (boys) 0.2/1,000 (girls)					
Projected Prevalence LD 18-64 2020	2018	PANSI	8,300					
People with autism who are eligible for social care	2018	CBMDC Social Care	256					
People who have both autism and LD who are eligible for social care	2018	CBMDC Social Care	26					
People who have both autism and mental illness who are eligible for social care	2018	CBMDC Social Care	14					

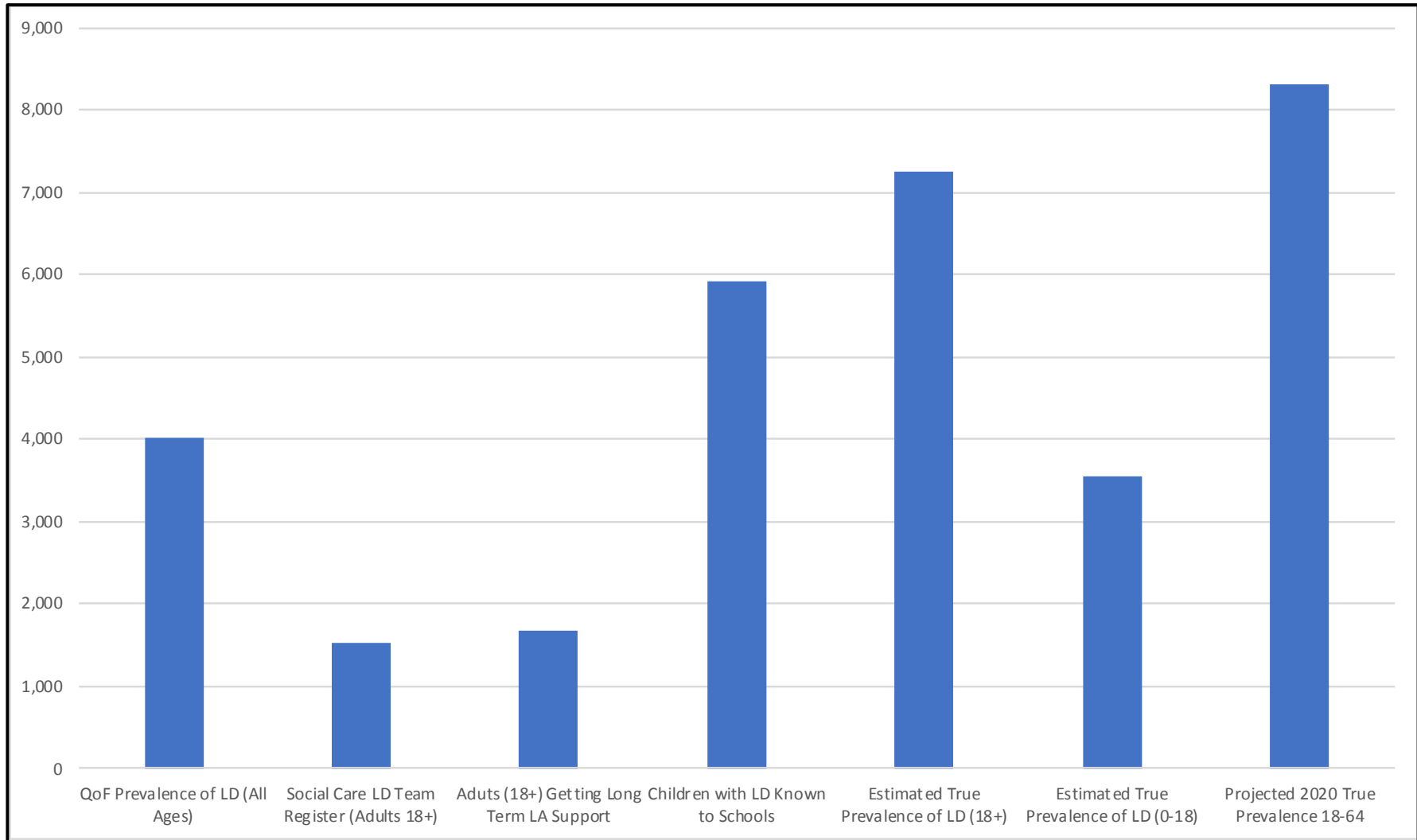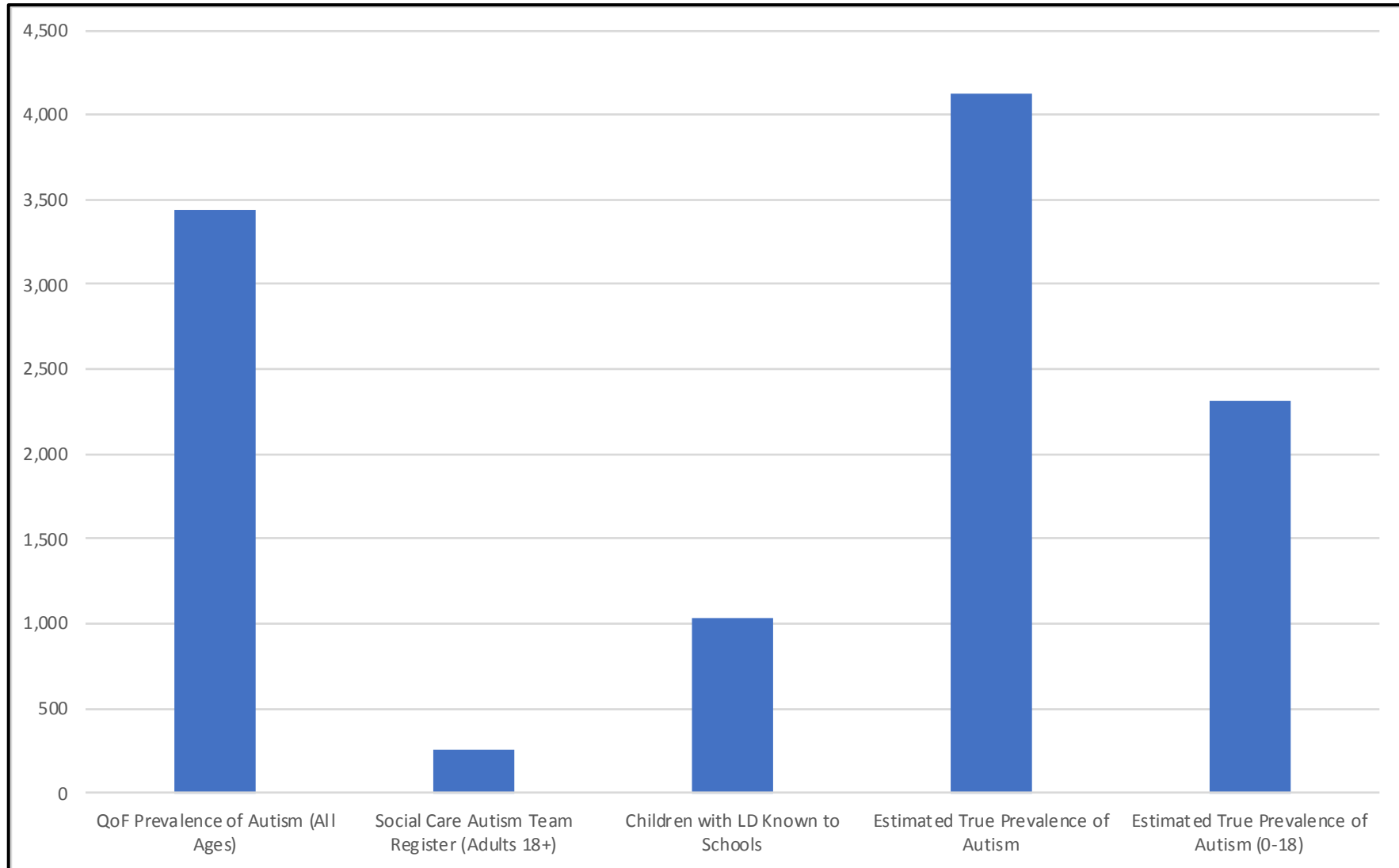**Figure 1**　　　　　　　　　　**Summary Figure of Key LD Statistics, Bradford 2018**

Figure 2

Summary Figure of Key Autism Statistics, Bradford 2018

What Does This Mean for People with LD and Autism in Bradford and Airedale?

Bradford is the youngest city in England, with children aged 0-4 the cohort that is expanding fastest, particularly in the most deprived areas. This will translate into challenges in equity of access and provision of services in coming years. Although both administrative and estimated totals are presented here, it is important to bear in mind the variation in need that exists across this population, and also that there are a considerable number of people with LD and Autism who do not come into contact with mainstream services where they will be recorded as having such a diagnosis. These people will require health and social care like any other group in the population, and it is crucial that appropriate adjustments are made for them in these scenarios.

It is clear that we can expect the cohort of people with LD and Autism to expand in size in coming years as people live longer, healthier lives. Planning should take heed of this and incorporate the findings of this report into developing strategic and operational initiatives.

Strategic Recommendations

1. **Work should continue to grow our understanding of the demographics and epidemiology of our population of people with LD and Autism**
2. **The data contained in this report should be used to inform capacity: demand modelling as new services develop**

REFERENCES

1. Last JM (2001). "A dictionary of epidemiology", 4th edn, Oxford: Oxford University Press. 5th. edn (2008)
2. Elder, J.H. et al., 2017. Clinical impact of early diagnosis of autism on the prognosis and parent-child relationships. *Psychology Research and Behavior Management*, 10, pp.283–292.
3. NICE Guideline 93: Learning disabilities and behaviour that challenges: service design and delivery. National Institute for Health and Care Excellence. 2018.
4. Gates, B., Contemporary, K.M.L.D.A.2016, Use of the term "learning disabilities" in the United Kingdom: issues for international researchers and practitioners. *repository.uwl.ac.uk*
5. Valuing People. A New Strategy for Learning Disability for the 21st Century. Department of Health. 2001.
6. https://www.mentalhealth.org.uk/learning-disabilities/a-to-z/l/learning-disabilities - last accessed 11/12/2018.

7. Maughan, B., Collishaw, S. & Pickles, A., 1999. Mild mental retardation: psychosocial functioning in adulthood. Psychological medicine, 29(2), pp.351–366.

8. Institute for Public Care; Projecting Adult Need and Service Information. IPC, 2014.

9. Emerson, E, Hatton C 2004. Lancaster University Institute for Health Research; Estimating the Current Need/Demand for Supports for People with Learning Disabilities in England

10. Germain N, Williams C. Learning Disability and Autistic Spectrum Disorder Health Needs Assessment. Doncaster Council. 2014.

11. Emerson E, Hatton C. People with Learning Disabilities in England. Centre for Disability Research, CeDR Research Report 2008:1 May 2008.

12. Hart, J.T., 1971. The inverse care law. The Lancet, 1(7696), pp.405–412.

13. Cooper, S.-A., Melville, C. & Morrison, J., 2004. People with intellectual disabilities. BMJ, 329(7463), pp.414–415.

14. Emerson E, Hatton C. Estimating Future Need for Social Care among Adults with Learning Disabilities in England: An Update. Learning Disabilities Observatory. 2010.

15. Emerson, E., 2012. Deprivation, ethnicity and the prevalence of intellectual and developmental disabilities. Journal of Epidemiology & Community Health, 66(3), pp.218–224.

16. Emerson E. Baines S. The Estimated Prevalence of Autism among Adults with Learning Disabilities in England. Learning Disabilities Observatory. 2010.

17. Baxter, A.J. et al., 2014. The epidemiology and global burden of autism spectrum disorders. *Psychological medicine*, 45(03), pp.601–613.

18. Graf, W.D. et al., 2017. The autism "epidemic": Ethical, legal, and social issues in a developmental spectrum disorder. *Neurology*, 88(14), pp.1371–1380.

19. https://www.cdc.gov/ncbddd/developmentaldisabilities/casedefinitions.html - accessed 25/06/17.

20. Lyall, K. et al., 2017. The Changing Epidemiology of Autism Spectrum Disorders. *Annual review of public health*, 38, pp.81–102.

21. Taylor, B., Jick, H. & MacLaughlin, D., 2013. Prevalence and incidence rates of autism in the UK: time trend from 2004-2010 in children aged 8 years. *BMJ Open*, 3(10), pp.e003219–6.

22. Baron-Cohen, S. et al., 2009. Prevalence of autism-spectrum conditions: UK school-based population study. *The British journal of psychiatry : the journal of mental science*, 194(6), pp.500–509.

23. Brugha, T.S. et al., 2011. Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of general psychiatry*, 68(5), pp.459–465.

24. Brugha, T.S. et al., 2016. Epidemiology of autism in adults across age groups and ability levels. *The British journal of psychiatry : the journal of mental science*, 209(6), pp.498–503.

25. Delobel-Ayoub, M. et al., 2015. Socioeconomic Disparities and Prevalence of Autism Spectrum Disorders and Intellectual Disability. *PLoS ONE*, 10(11), p.e0141964.

26. Gee, A., 2010. Californian autism clusters leave researchers baffled. *Lancet*, 376(9751), pp.1451–1452.

27. Kawa, R. et al., 2017. European studies on prevalence and risk of autism spectrum disorders according to immigrant status-a review. *European Journal of Public Health*, 27(1), pp.101–110.

Section 3 - Strategy, Policy and Guidance

National Policy

In 2001 the UK Government set out an action plan that they hoped would improve the lives of everyone affected by learning disabilities. By publishing the white paper Valuing People [1], they hoped to set out new initiatives that would pave the way for positive changes for people with learning disabilities, as well as their families and carers. The Valuing People paper is broken down into 11 objectives, with the first chapter mainly dedicated to issues and initiatives for children with learning disabilities. The remaining ten chapters focus primarily on the challenges and proposed improvements and support for adults with learning disabilities. The Valuing People white paper was primarily set out on a five-year action plan from 2001. By publishing this white paper, the UK Government were clearing setting out their intentions to improve services and support for the learning disabled from birth through to old age. The basic goal of the initiative published reinforced four main beliefs of the UK Government at the time:

- That people with learning disabilities should have equal legal and civil rights
- That people with learning disabilities should be given the chance and the means to lead more independent lives
- That people with learning disabilities should have more choice and be able to express and achieve their preferences
- That people with learning disabilities should be included in mainstream society

In September 2008 the Government published Valuing People Now [2], the Government's three-year big plan to improve the lives of people with learning disabilities and their families. in particular, this strategy:

- Addresses what people have told us about the support people with learning disabilities and their families need
- Reflects the changing priorities across government which impact directly on people with learning disabilities
- Sets out the government's response to the ten main recommendations in Healthcare for All, the report of the independent inquiry into access to healthcare for people with learning disabilities, and
- Provides a further response to the Joint Committee on Human Rights report, A Life Like Any Other [3]

The Government and NHS England have committed to reducing health inequalities for people with learning disabilities and have established national programmes to improve treatment and outcomes. The Government's Mandate to the NHS 2018-19 [4] set an objective for the NHS to close the health gap between people with mental health problems, learning disabilities and autism and the population as a whole.

In June 2015, NHS England commissioned the **National Learning Disability Mortality Review Programme** led by the University of Bristol, to review and learn from deaths of people with a learning disability with the aim of improving services, care and support nationally. The Department of Health has established a **Confidential Inquiry Into The Premature Deaths of People with Learning Disabilities** [5]. The Inquiry investigated the avoidable or premature deaths of people with learning disabilities through a series of retrospective reviews of deaths. The project, now in its fourth year, is investigating the causes of premature mortality for people with a learning disability and has produced recommendations to reduce this inequality.

The **Government's Response to the Confidential Inquiry into Premature Deaths of People with Learning Disabilities** [6], stated that the Department of Health is committed to addressing the issues identified by the Confidential Inquiry in order to improve the quality of care and outcomes for people with learning disabilities and family carers. The response set actions to be delivered by the Department of Health, NHS England, Public Health England and other statutory organisations, under each of the 18 recommendations. Progress on these actions is monitored by the **Learning Disability Programme Board**.

In 2011, the BBC's Panorama programme exposed the abuse of patients at Winterbourne View, an independent hospital for people with learning disabilities and/or autism. Further inspections by the CQC of 150 hospitals and care homes for people with a learning disability found inadequate practice in some services, included poor person-centred care, limited appropriate activities and a lack of monitoring and learning from incidents of restraint. The Department of Health's national policy response, **Transforming Care: A National Response to Winterbourne View Hospital** [7] stated that **"hospitals are not where people should live"** and pledged that everyone inappropriately in hospital should move to community-based support as quickly as possible, and no later than 1 June 2014.

The Government and NHS England have also committed to reducing the number of people with a learning disability who are placed in inpatient services. NHS England's **Transforming Care Programme** intends to improve the quality of life of those with learning disabilities by substantially reducing the number of people placed in hospital, reducing the length of time those admitted spend there, and enhancing the quality of both hospital and community settings. It also sets out plans to close the last remaining standalone learning disabilities hospital in England.

In February 2015, the National Audit Office (NAO) published its report **Care Services for People with Learning Disabilities and Challenging Behaviour**. The report found that the Government had not met its central goal of moving people with learning disabilities and challenging behaviour out of hospital by 1 June 2014, because it "underestimated the complexity and level of challenge in meeting the commitments in its action plan".

During a Public Accounts Committee evidence session on the NAO report in February 2015, the Chief Executive of NHS England announced that there would now be a planned closure programme for NHS mental health hospitals, and a change in commissioning practices for NHS inpatients within the independent sector. This would be accompanied by a transition plan for the people with learning disabilities within these hospitals, from 2016–17.

Since June 2016, the Department of Health & Social Care has published independently assured, ratings of the quality of healthcare offered to people with learning disabilities in all CCG areas, to highlight variations and to allow rapid action to be taken when improvement is needed.

In October 2015, NHS England, in partnership with the Local Government Association (LGA) and the Directors of Adult Social Services (ADASS), published a national action plan to develop community services and close inpatient facilities for people with a learning disability and/or autism. The **Building the Right Support** plan [8] aims to shift money from inpatient services to the community, and reduce use of inpatient beds by 35% - 50% in the next 3 years, alongside closure of the last standalone learning disability hospital in England, Calderstones.

NHS England and NHS Employers are working together on a national programme to support NHS organisations to increase employment of people with learning disabilities in the NHS.

Autism Act 2009 [9]
Parliamentary legislation stating that the SoS must prepare and publish a document (i.e. a National Autism Strategy) setting out a strategy for meeting the needs of adults in England with autistic spectrum conditions by improving the provision of relevant services to such adults by local authorities, NHS bodies and NHS foundation trusts

Fulfilling and Rewarding Lives 2010 [10]
Published in March 2010, Fulfilling and rewarding lives: the strategy for adults with autism in England set a clear framework for all mainstream services across the public sector to work together for adults with autism.
'Fulfilling and rewarding lives' sets out seven quality outcome measures against which local areas in England can test how well they are meeting the aims of the Autism Strategy. These outcomes state that autistic adults will:
1. Achieve better health outcomes
2. Be included and economically active
3. Live in accommodation that meets their needs
4. Benefit from the personalisation agenda in health and social care, and be able to access personal budgets
5. No longer be inappropriately managed in the criminal justice system

6. Be satisfied with local services
7. Be involved in service planning.

To help local areas work towards these outcomes, the document also sets out three key ambitions:
1. Local Authorities and partners know how many adults with autism live in the area.
2. A clear and trusted diagnostic pathway is available locally.
3. Health and social care staff make reasonable adjustments to services to meet the needs of adults with autism.

Other actions in the autism strategy include:
- A new National Autism Programme Board to lead change in public services set out in the strategy
- A programme to develop training with health and social care professional bodies (backed by a £500,000 investment)
- Autism awareness training for all Job Centre Disability Employment Advisers
- Guidance on making public services accessible for adults with autism, like improving buildings, public transport and communication
- A clear, consistent pathway for diagnosis.

The strategy was followed in December 2010 by statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy and then in April 2011 by a guidance and self-assessment framework is to help support Local Authorities and NHS organisations and their partners to implement the statutory guidance in their localities.

In April 2014, the government published Think Autism [11] and update to the national strategy, reflecting the changes that had come about in the years since its publication. From this, fifteen priority Challenges For Action were identified by people with autism, carers, professionals and others who work with people with autism, these being:
1. I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism.
2. I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others.
3. I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low level support.
4. I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism.

5. I want to be safe in my community and free from the risk of discrimination, hate crime and abuse.
6. I want to be seen as me and for my gender, sexual orientation and race to be taken into account.
7. I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.
8. I want autism to be included in local strategic needs assessments so that person centred local health, care and support services, based on good information about local needs, is available for people with autism.
9. I want staff in health and social care services to understand that I have autism and how this affects me.
10. I want to know that my family can get help and support when they need it.
11. I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies.
12. I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging.
13. If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.
14. I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible.
15. I want support to get a job and support from my employer to help me keep it.

Local Policy and Strategy

Bradford and Craven Autism Including Other Neurodiversity Strategy 2016 [12]
This strategy primarily focuses on the development of services for people with autism although it also considers other frequently co-occurring neurodevelopmental conditions across the age spectrum. The strategy upholds the need to focus on a holistic, joined-up approach across statutory and non-statutory services in order to ensure support and care is efficiently delivered and effectively utilised.

The main <u>focus</u> of this strategy is to **enable people that are neuro-diverse to keep well and safe and to live fulfilling lives**. The <u>purpose</u> of the strategy is to outline what care and support is required by service users and their families, recognising that resources are finite, and to progress the key recommendations outlined in the government's "Think Autism" strategy (see above [11]). Twelve key areas for review were identified, these being:

1. Data/information
2. Autism Awareness/training
3. Defining a Pathway
4. Learning Disabilities & Mental Health
5. Transition
6. Education and support
7. Relationships/Carers/Families
8. Employment
9. Housing
10. Undiagnosed/late diagnosis
11. Older Adults
12. Accessing mainstream services

Recommendations and requirements are identified for each of these areas.
Priority outcomes identified were as follows:

1. Local organisations and services have a better awareness and understanding of autism and make reasonable adjustments so that mainstream services are more accessible to, and respond more appropriately to, children and adults with autism.
2. A clear and consistent diagnostic pathway exists, across the age spectrum, with pre and post-diagnostic support where appropriate/needed
3. Digital resources and technology are available to support people with autism to access mainstream services or to seek support or advice when it is needed should be utilised and/or developed
4. All children/adults with autism and their carers are able to access appropriate information and advice about services available to them and that these are available within appropriate timescales
5. Transition points in services are reviewed and improvements made as they can cause particular upset and distress for people with autism. For example support

for young people with autism as they move into adulthood and into older adulthood

6. Data and information systems capture key information about people with autism to ensure integrated pathways and to enable better understanding of need in the District.
7. Adults with autism are able to be supported in their preparation for work and are able to access employment opportunities and relevant support at work
8. Local planning and leadership is in place in relation to the provision of services for people with autism and their families (and this is effectively co-ordinated across public sector services)
9. Opportunities to better utilise limited resources, particularly specialist resources, are maximised - this may include collaboration with neighbouring districts.

Bradford Learning Disabilities Transformation Plan [13]
Bradford Learning Disabilities Transformation Plan is an all age change programme focusing on improving services for people with learning disabilities, including those who may have autism, who display behaviour that challenges, and including those with a mental health condition. The programme is designed to drive system-wide change and enable more people with a learning disability who have complex behaviour presentations to:

- Have a home within their community
- Be able to develop and maintain relationships
- Get the support they need to live healthy, safe and rewarding lives

The plan was developed with involvement from the Learning Disabilities Partnership Board and Autism Partnership Board and with links to existing structures. Integrated personalisation, co-production, engagement and communication with people with learning disabilities and/or autism and family carers are embedded across the programme.

The programme is led by a series of workgroups, these being:

- Workforce development group
- Finance and activity task and finish group
- Healthier Lives reference group
- Children and young people task and finish group
- Early intervention and prevention (children and young people)
- Early intervention, prevention (adults) & community service model task & finish group
- Market shaping
- Data and information task and finish group
- Engagement task and finish group
- Communications group
- Experts by Experience, families and carers

Transforming Care for People with Learning Disabilities

Although strictly speaking a national programme, mandated by NHS England and other national partners, responsibility for delivery of this programme has been delegated to local Transforming Care Programme Boards, in this case the Bradford TCPB.

The programme was commissioned with a view to accelerating the transformation that we, people with learning disabilities and their families are looking for, and aims to improve the lives of children, young people and adults with a learning disability and/or autism who display behaviours that challenge, including those with a mental health condition.

The programme has three key aims:

- To improve quality of care for people with a learning disability and/or autism
- To improve quality of life for people with a learning disability and/or autism
- To enhance community capacity, thereby reducing inappropriate hospital admissions and length of stay

To support TCPs a service model has been published to describe 'what good looks like' in services and support. The model is structured around nine principles seen from the point of view of a person with a learning disability and/or autism:

1. I have a good and meaningful everyday life.
2. My care and support is person-centred, planned, proactive and coordinated.
3. I have choice and control over how my health and care needs are met.
4. My family and paid support and care staff get the help they need to support me to live in the community.
5. I have a choice about where I live and who I live with.
6. I get good care and support from mainstream health services
7. I can access specialist health and social care support in the community.
8. If I need it, I get support to stay out of trouble.
9. If I am admitted for assessment and treatment in a hospital setting because my health needs can't be met in the community, it is high-quality and I don't stay there longer than I need to.

Home First

The Bradford Home First Strategy [14] has been designed by Bradford Council to ensure that:

"where possible, people in the Bradford District who are in receipt of health and social care services should be supported to stay in their own home, so that they can continue to enjoy relationships with their family, friends and be active members of their local community while being able to participate in activities in the wider District".

The Council will work with people who choose to access support from services, their carers and family members and our communities to develop new systems which build on their strengths. Strengths based approaches involve:

- Making information and advice easily accessible so that people can make informed decisions about their support needs
- Early intervention which builds on people's natural networks of support
- Ensuring that all practicable steps are taken to ensure the wishes, feelings and beliefs of people who have long term support needs from the services are communicated, understood and upheld

Guidance

NICE Guidelines

NICE guidelines make evidence‑based recommendations on a wide range of topics, from preventing and managing specific conditions, improving health, and managing medicines in different settings, to providing social care and support to adults and children, and planning broader services and interventions to improve the health of communities. They aim to promote individualised care and integrated care (for example, by covering transitions between children's and adult services and between health and social care).

There are seven NICE Guidelines that cover LD and Autism:

1. **NG11 - Challenging Behaviour and Learning Disabilities: Prevention and Interventions for People with Learning Disabilities whose Behaviour Challenges (May 2015)** [15]

   This guideline covers interventions and support for children, young people and adults with a learning disability and behaviour that challenges. It highlights the importance of understanding the cause of behaviour that challenges, and performing thorough assessments so that steps can be taken to help people change their behaviour and improve their quality of life. The guideline also covers support and intervention for family members or carers.

2. **NG54 - Mental Health Problems in People with Learning Disabilities: Prevention, Assessment and Management (September 2016)** [16]

   This guideline covers preventing, assessing and managing mental health problems in people with learning disabilities in all settings (including health, social care, education, and forensic and criminal justice). It aims to improve assessment and support for mental health conditions, and help people with learning disabilities and their families and carers to be involved in their care.

3. **NG93 – Learning Disabilities and Behaviour that Challenges: Service Design and Delivery (March 2018)** [17]

   This guideline covers services for children, young people and adults with a learning disability (or autism and a learning disability) and behaviour that challenges. It aims to promote a lifelong approach to supporting people and their families and carers, focusing on prevention and early intervention and minimising inpatient admissions.

4. **NG96 – Care and Support of People Growing Older with Learning Disabilities (April 2018)** [18]

   This guideline covers care and support for adults with learning disabilities as they grow older. It covers identifying changing needs, planning for the future, and delivering services including health, social care and housing. It aims to support people to access the services they need as they get older.

5. **CG128 - Autism Spectrum Disorder in Under 19s: Recognition, Referral and Diagnosis (December 2017 Update)** [19]
   This guideline covers recognising and diagnosing autism spectrum disorder in children and young people from birth up to 19 years. It also covers referral. It aims to improve the experience of children, young people and those who care for them.

6. **CG142 Autism Spectrum Disorder in Adults:Diagnosis & Management (June 2012)** [20]
   This guideline covers the care provided by primary, community, secondary, tertiary and other health and social care professionals who have direct contact with, and make decisions concerning the care of, adults with autism.

7. **CG170 - Autism Spectrum Disorder in Under 19s: Support and Management (August 2013)** [21]
   This guideline covers children and young people with autism (across the full range of intellectual ability) from birth until their 19th birthday, and their parents and carer

NICE Quality Standards

NICE quality standards are a concise set of prioritised statements designed to drive measurable improvements in the 3 dimensions of quality – patient safety, patient experience and clinical effectiveness – for a particular area of health or care. They are derived from high-quality guidance, such as that from NICE or other sources accredited by NICE

There are three NICE Quality Standards that cover LD and Autism:

1. **QS101 - Learning Disabilities: Challenging Behaviour (October 2015)** [22]
   This quality standard covers care and support for adults, young people and children with a learning disability and behaviour that challenges. It also includes support for families and carers. It describes high-quality care in priority areas for improvement.
   The Quality Statements are as follows:
   Statement 1. People with a learning disability have a comprehensive annual health assessment from their GP.
   Statement 2. People with a learning disability and behaviour that challenges have an initial assessment to identify possible triggers, environmental factors and function of the behaviour.
   Statement 3. People with a learning disability and behaviour that challenges have a designated person responsible for coordinating the behaviour support plan and ensuring that it is reviewed.

Statement 4. People with a learning disability and behaviour that challenges take part in personalised daily activities.

Statement 5. People with a learning disability and behaviour that challenges have a documented review every time a restrictive intervention is used.

Statement 6. People with a learning disability and behaviour that challenges only receive antipsychotic medication as part of treatment that includes psychosocial interventions.

Statement 7. People with a learning disability and behaviour that challenges have a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment and then at least every 6 months.

Statement 8. Parents or carers of children aged under 12 years with a learning disability and behaviour that challenges are offered a parent-training programme.

2. **QS142 - Learning disabilities: Identifying and Managing Mental Health Problems (January 2017) [23]**

This quality standard covers the prevention, assessment and management of mental health problems in people with learning disabilities in all settings (including health, social care, education, and forensic and criminal justice). It also covers family members, carers and care workers.

The Quality Statements are as follows:

Statement 1: Young people and adults with learning disabilities have an annual health check that includes a review of mental health problems.

Statement 2: People with learning disabilities who need a mental health assessment are referred to a professional with expertise in mental health problems in people with learning disabilities.

Statement 3: People with learning disabilities and a serious mental illness have a key worker to coordinate their care.

Statement 4: People with learning and mental health problems who are receiving psychological interventions have them tailored to their preferences, level of understanding, and strengths and needs.

Statement 5: People with learning disabilities who are taking antipsychotic drugs that are not reduced or stopped have annual documentation on reasons for continuing this prescription.

3. **QS51 - Autism (January 2014) [24]**

This quality standard covers health and social care services for adults, young people and children with autism. It includes assessment and diagnosis of autism spectrum disorders, and care and support for people diagnosed with an autism spectrum disorder. It describes high-quality care in priority areas for improvement.

The Quality Statements are as follows:

Statement 1: 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.

Statement 2: People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.

Statement 3: People with autism have a personalised plan that is developed and implemented in a partnership between them and their family and carers (if appropriate) and the autism team.

Statement 4: People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.

Statement 5: People with autism have a documented discussion with a member of the autism team about opportunities to take part in age-appropriate psychosocial interventions to help address the core features of autism.

Statement 6: People with autism are not prescribed medication to address the core features of autism.

Statement 7: People with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.

Statement 8: People with autism and behaviour that challenges are not offered antipsychotic medication for the behaviour unless it is being considered because psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour.

Key Therapeutic Topics

NICE Key Therapeutic Topics (KTTs) are quality-assured summaries of the evidence base on topics identified to support medicines optimisation.

There is one NICE KTT covering that cover LD and Autism:

4. **KTT19 - Psychotropic Medicines in People with Learning Disabilities whose Behaviour Challenges (January 2017)**

The NICE guideline recommends considering medicines, or optimising existing medicines, for coexisting mental or physical health problems identified as a factor in the development and maintenance of behaviour that challenges. The guidance recommends considering antipsychotic medicines to manage behaviour that challenges only if:

- Psychological or other interventions alone do not produce change within an agreed time or
- Treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour or

- The risk to the person or others is very severe (for example, because of violence, aggression or self-injury).

What does this mean for people with Learning Disabilities and Autism in Bradford?

LD and Autism are replete with policy and guidance documents which can help us deliver high quality care to those who need it. Nonetheless, these documents can be difficult to navigate and to combine into discrete planning and operational frameworks. In particular, NICE guidance can seem at times conflicting and difficult to relate to local operations. Another clear challenge is deciding on the relative position and priority of LD and Autism documents as combined strategic approaches will not always be appropriate.

Strategic Recommendation

1. A workstream should be established to map and combine national and local strategic, policy and guidance documents into a format that can be easily referenced and applied locally. This piece of work should sit directly underneath the Transforming Care Partnership Board

---

REFERENCES:
1. Valuing People. A New Strategy for Learning Disability for the 21st Century. Department of Health. 2001.
2. Valuing People Now. Summary Report March 2009-September 2010. Department of Health. 2010.
3. A Life Like Any Other? Human Rights of Adults with Learning Disabilities. House of Lords House of Commons Joint Committee on Human Rights. 2008.
4. NHS Mandate 2018 to 2019. Department of Health and Social Care. 2018.
5. Heslop P, Blair B. Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) Final report. Department of Health. 2013.
6. Government response to the Confidential Inquiry into premature deaths of people with learning disabilities. Department of Health. 2013.
7. Transforming care: A national response to Winterbourne View Hospital Department of Health Review: Final Report. Department of Health. 2012.
8. Building The Right Support. A National Plan to Develop Community and Close Inpatient Services for People with a Learning Disability and/or Autism who Display Behaviour that Challenges, Including Those with a Mental Health Condition. Local Government Association, NHS England. October 2015.
9. HM Government. Autism Act. 2009.
10. Department of Health (2010) '"Fulfilling and rewarding lives": the strategy for adults with autism in England', London: Department of Health.

11. Department of Health (2014) 'Think autism: fulfilling and rewarding lives, the strategy for adults with autism in England: an update', London: Department of Health.
12. Bradford District and Craven Autism including other Neurodiversity Strategy. Bradford Council Children's Services. 2017
13. Transforming Care for People with Learning Disabilities in Bradford, Airedale, Wharfedale and Craven, Next Steps. Bradford Council. 2017.
14. Home First: Our Vision for Wellbeing. Bradford Council. 2018
15. NICE Guideline 11. Challenging Behaviour and Learning Disabilities: Prevention and Interventions for People with Learning Disabilities whose Behaviour Challenges. National Institute for Health and Care Excellence. 2015.
16. NICE Guideline 54 - Mental Health Problems in People with Learning Disabilities: Prevention, Assessment and Management. National Institute for Health and Clinical Excellence. 2016.
17. NICE Guideline 93. Learning Disabilities and Behaviour that Challenges: Service Design and Delivery. National Institute for Health and Clinical Excellence 2018
18. NICE Guideline 96. Care and Support of People Growing Older with Learning Disabilities. National Institute for Health and Care Excellence. 2018
19. Clinical Guideline 128. Autism Spectrum Disorder in Under 19s: Recognition, Referral and Diagnosis (December 2017 Update). National Institute for Health and Care Excellence. 2017
20. Clinical Guideline 142. Autism Spectrum Disorder in Adults: Diagnosis & Management. National Institute for Health and Care Excellence. 2012.
21. Clinical Guideline 170 - Autism Spectrum Disorder in Under 19s: Support and Management. National Institute for Health and Care Excellence. 2013
22. Quality Standard 101 - Learning Disabilities: Challenging Behaviour. National Institute for Health and Care Excellence. 2015
23. Quality Standard 142 - Learning disabilities: Identifying and Managing Mental Health Problems. National Institute for Health and Care Excellence. 2017
24. Quality Standard 51 – Autism. National Institute for Health and Care Excellence. 2014
25. Key Therapeutic Topic 19. Psychotropic Medicines in People with Learning Disabilities whose Behaviour Challenges. 2017

Section 4 - Primary Care

GPs are funded to hold a register of adults with a LD, this being the Quality Outcomes Framework (QOF) Register. It has been suggested that, in England, only around a quarter of affected adults are on the LD QOF register at their local general practice [1]. In 2016/17 there were **3,607** people (all ages) registered on the QOF for Bradford, Airedale and Craven, as at October 2018, this had grown to **4,098** people, an increase of **11.7%** in 18 months. This rise is more likely due to increased awareness and improved case finding as opposed to a real increase in prevalence. The distribution of the register across the three Bradford CCGs is shown in Table 1 below.

Table 1   Learning Disability QOF Register, Bradford CCGs, October 2018

CCG	Number	% of Bradford Diagnoses	Crude Rate/1,000 pop.
AWCCCG	886	22.0%	5.6
BCCCG	995	24.7%	7.1
BDCCG	2,147	53.3%	6.4
TOTAL	4,028		

Autism is not currently included on the QOF, however figures were obtained as to currently recorded diagnoses in Primary Care for Bradford, the figure being **3,341** (all ages). The distribution of these across the three Bradford CCGs is shown in Table 2 below.

Table 2   Autism QOF Register, Bradford CCGs, October 2018

CCG	Number	% of Bradford Diagnoses	Crude Rate/1,000 pop.
AWCCCG	1,039	30.2%	6.5
BCCCG	463	13.5%	3.3
BDCCG	1,939	56.3%	5.8
TOTAL	3,441		

Access to Primary Healthcare

In the UK, a number of initiatives in primary care have addressed the need to improve the health of people with LD. In particular, GP Practices are expected to make **reasonable adjustments** to improve access to care for people with LD.

A 2016 UK study used primary care data from England to describe chronic disease, comorbidity, disability, and general practice use for adults with LD, and to compare these to the general population [2]. Specifically, consultation length and continuity of care were examined as they are potentially important areas that can be adjusted in order to improve the primary care experience for people with LD. The authors found that, compared with the general population, people with LD have generally higher overall levels of chronic disease and **greater primary care use**. The study concluded that ensuring access to high-quality chronic disease management, particularly for **epilepsy** and **mental illness**, can help address these greater healthcare needs. It was also suggested that continuity of care and longer appointment times are important potential improvements in primary care.

Use of Primary Care Services in Bradford

A study carried out in Bradford in 2017 [3] described the extent and characteristics of use of Bradford Health Services by people with LD, and shows the number of people who have attended Primary Care services on at least one occasion, stratified by the risk of attending. This is illustrated in Table 3 and Figure 1 below.

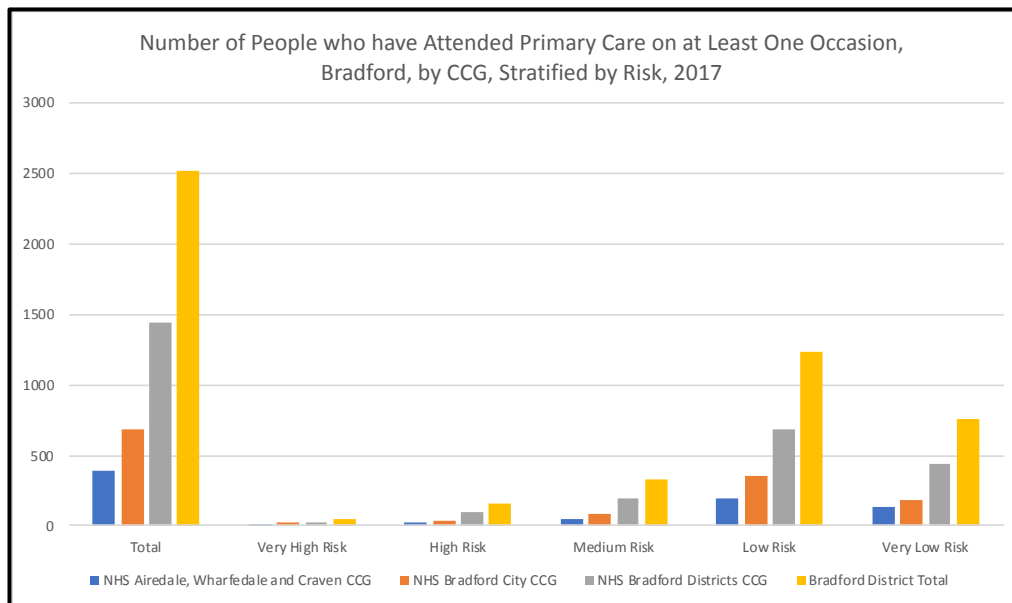**Table 3** **People with Learning Disability Attending Primary Care on at Least one**

Occasion, Bradford, by CCG, 2017

CCG	Total	Very High Risk	High Risk	Medium Risk	Low Risk	Very Low Risk
NHS Airedale, Wharfedale and Craven CCG	396	5	18	47	191	135
NHS Bradford City CCG	684	21	38	87	354	184
NHS Bradford Districts CCG	1441	27	101	194	685	434
Bradford District Total	**2521**	53	157	328	1230	753

As can be seen, the majority of people are low risk or very risk, with a stepwise downward pattern in numbers as risk increase from low risk. In addition, the Bradford District total number of attenders (**2,521**) is significantly lower than the QOF figure for LD of **4,028** (See Section 3 – Epidemiology). This can be interpreted in a number of ways. It would be easy to assume that the 1,500 or so people with LD who did not attend their GP did so because their health is good and they have no need to be seen. On the other hand, given that people with LD are known to have poorer health than other people, the findings may be due to a manifestation of the Inverse Care Law [x] whereby we know that those in most need are the least likely to access care and thus present in extremis or as a crisis or Accident and Emergency presentation.

Figure 1   People with Learning Disability Attending Primary Care on at Least one

Occasion, Bradford, by CCG, 2017

Number of People who have Attended Primary Care on at Least One Occasion, Bradford, by CCG, Stratified by Risk, 2017

Legend: NHS Airedale, Wharfedale and Craven CCG | NHS Bradford City CCG | NHS Bradford Districts CCG | Bradford District Total

Health Checks

The NHS Health Check is a health check-up for adults in England aged 40-74. It is designed to spot early signs of stroke, kidney disease, heart disease, type 2 diabetes or dementia. As people age, the risk of developing one of these conditions rises - An NHS Health Check helps find ways to lower this risk. People in the 40-74 age group without a pre-existing condition, receive a letter inviting them for a Health Check every five years.

Key Statistics [4]

- People with LD have **poorer physical and mental health** than other people. This is **not inevitable**.
- The **average age of death** for people with a LD is **65 for men** and **63 for women**. (Average age of death of **78 for men** and **83 for women** in the general population)
- **37%** of people with a learning disability die from **avoidable causes**, compared with **8.8%** of the general population
- Only **49%** of adults with a learning disability on the GP or health register in England received an **annual health check** in 2014-15
- Annual health checks **can reduce health inequalities**, but not enough people with a learning disability get them

Those registered with a GP as having a LD should be offered an annual health check under the Enhanced Service (ES). A Lancet study [5] has demonstrated that those people with LD who have a health check show:
- Increased rates of general and specific health assessments
- Increased identification of co-morbidities

- More health action plans and secondary care referrals

The ES mandates that practices should invite all patients on the health check register for a review of physical and mental health annually. As a minimum the health check should include:

- A collaborative review with the patient and carer (where applicable) of physical and mental health including: health promotion, chronic illness and symptoms enquiry; physical examination; epilepsy, dysphagia, behaviour and mental health and specific syndrome check
- Accuracy and appropriateness of prescribed medication checked
- A review of co-ordination arrangements with secondary care
- A review of transition arrangements (where appropriate).
- A review of communication needs
- A review of family and carer needs
- Support for the patient to manage their own health and make decisions about the health and healthcare

NHS England has stated that our ambition should be:

1. To increase the number of people with a LD (all ages) identified on GP registers – **10%** increase year on year (Bradford **11.7%** increase in 18 months – see above)
2. For 75% of those on GP registers, and eligible for health checks, to have had one – by March 2020. Table X below shows that Bradford has a health check rate for people with LD of 58.4%, comfortably the highest performance in the region.

Table 4

Area	Value		Lower	Upper
England	48.9		48.6	49.1
Yorkshire and the Humber region	44.3		43.6	45.1
Barnsley	37.5		34.4	40.8
Bradford	58.4		55.9	60.9
Calderdale	47.6		43.7	51.6
Doncaster	46.4		43.2	49.8
East Riding of Yorkshir...	45.8		42.5	49.4
Kingston upon Hull	32.2		29.5	35.1
Kirklees	45.6		43.2	48.1
Leeds	43.3		41.2	45.5
North East Lincolnshire	36.1		32.4	40.0
North Lincolnshire	51.6		46.7	56.9
North Yorkshire	42.0		39.7	44.4
Rotherham	49.8		46.3	53.5
Sheffield	37.2		35.3	39.1
Wakefield	44.9		42.2	47.8
York	39.4		34.8	44.4

Source: NHS Digital

Recently, a qualitative study undertaken by Healthwatch in the South West of England recruited 52 people who had had a recent Annual Health Check, and despite some limitations, made recommendations to [6]:

- Build trust and help people take personal responsibility for their health. Health professionals should talk to the individual and not just their support.
- Promote the annual health checks via a flyer being sent out with an Easy read letter.
- Take up reminder calls about appointments to reduce the number of missed appointments.
- Give each individual an Easyread 'Action from Health Check' document at the end of each appointment (available at www.easyhealth.org).
- Provide choice and consistency in who supports them during their annual health check.
- Ask people prior to their annual health check if there are any special adjustments (e.g. consideration to waiting areas and times).
- Provide extra reassurance and explanation about what is happening to them and why.
- Offer an option for people to speak privately without support at some point during an individual's annual health check.

What Does This Mean for people with LD and Autism in Bradford and Airedale?

Primary care is the key interface for clinicians and patients in respect of health care and early presentation of illness. It is crucial that GPs and other primary care staff are appropriately equipped to recognise and manage those people with LD and Autism who present to them. They must also be trained and resourced to make adjustments for their patients with LD and Autism as required. Proportion of people with LD and Autism varies across CCGs, likely due to differences in demographics/
Health checks remain the key vehicle for maintaining the good health of our people with LD and Autism in the community. They also provide the key means of minimising health inequalities in this group. This should be recognised and prioritised strategically

> **Strategic Recommendations**
> 1. **LD and Autism should remain high on the priority list for all three CCGS.**
> 2. **CCGs should plan robustly for coming rises in demand for their services from people with LD and Autism**
> 3. **CCGs should support work to maximise the impact of NHS Health Checks on reducing health inequalities in people with LD and Autism.**

REFERENCES:

1. Russell, A.M., Bryant, L. & House, A., 2017. Identifying people with a learning disability: an advanced search for general practice. *The British Journal of General Practice*: 67(665), pp.e842–e850.
2. Carey, I.M. et al., 2016. Health characteristics and consultation patterns of people with intellectual disability: a cross-sectional database study in English general practice. *The British Journal of General Practice* :66(645), pp.e264–70.
3. Dr Foster Study
4. Elliott K. The Learning Disability Health Check. NHS England. 2014
5. Buszewicz, M. et al., 2014. Assessment of an incentivised scheme to provide annual health checks in primary care for adults with intellectual disability: a longitudinal cohort study. *The Lancet Psychiatry*, 1(7), pp.522–530.
6. Healthwatch Cornwall

Section 5 - Secondary Care

People with LD and Autism will, like most people, require admission to hospital on occasion, either on an elective basis or as an emergency. Reducing the numbers of emergency in any population of people is a strategic aim on a national basis [1]. There is, however, evidence that inpatient care for people with LD is of insufficient quality and needs to be improved [2].

A key UK study of inpatient care of people with LD published in 2016 found that:

- A swallowing assessment was completed in less than 20% people with LD (given the prevalence of dysphagia in this group, some form of swallow assessment is fundamental to the care of people with LD in an inpatient setting [3, 4])
- Epilepsy risk assessments were similarly neglected (epilepsy and convulsions are leading causes of death in people with LD and clinical guidelines for management in this group stress the importance of epilepsy risk assessment in mitigating the risk of harm from the condition)
- Health passports, or similar forms of patient-held health record, had been used in only a minority of cases

Additionally, a 2013 study carried out by the Learning Disabilities Observatory [5] found that, in admissions for Ambulatory Care Sensitive Conditions (conditions which, given 'effective management' at the primary care level, should not normally result in an admission to hospital) for people with Learning Disabilities in England:

- For people with learning disabilities, about **8 out of every 100** admissions are emergencies that might be preventable.
- For people who don't have learning disabilities, it is about **5 out of every hundred**.
- For people with learning disabilities this happens to adults of all ages.
- For people who don't have learning disabilities, it is mainly a problem for older people.
- The commonest cause for people with learning disabilities is convulsions and epilepsy.
- At any time in England there are about 75 people with learning disability in hospital as an emergency for this reason.
- Other common causes for people with learning disabilities are constipation, diabetes and influenza/pneumonia.
- Hospital admissions for emergencies that could usually be prevented are longer than other admissions.
- This is the same for people with learning disabilities as for other people.

Tables 1 to 4 and figures 1 to 4 below are derived from a study carried out in Bradford in 2017 to describe the extent and characteristics of use of our Acute Trusts to manage emergencies in people with LD.

Emergency Care

Risk of Emergency Admission

Tables 1 to 4 show stratified risks of admission across Bradford as a District and our individual CCGs. The picture remains similar across all 4 of these, with the **largest group being those with a low risk** of emergency admission, the second highest group being those with a low risk and then a stepped reduction as risk increases to very high risk.
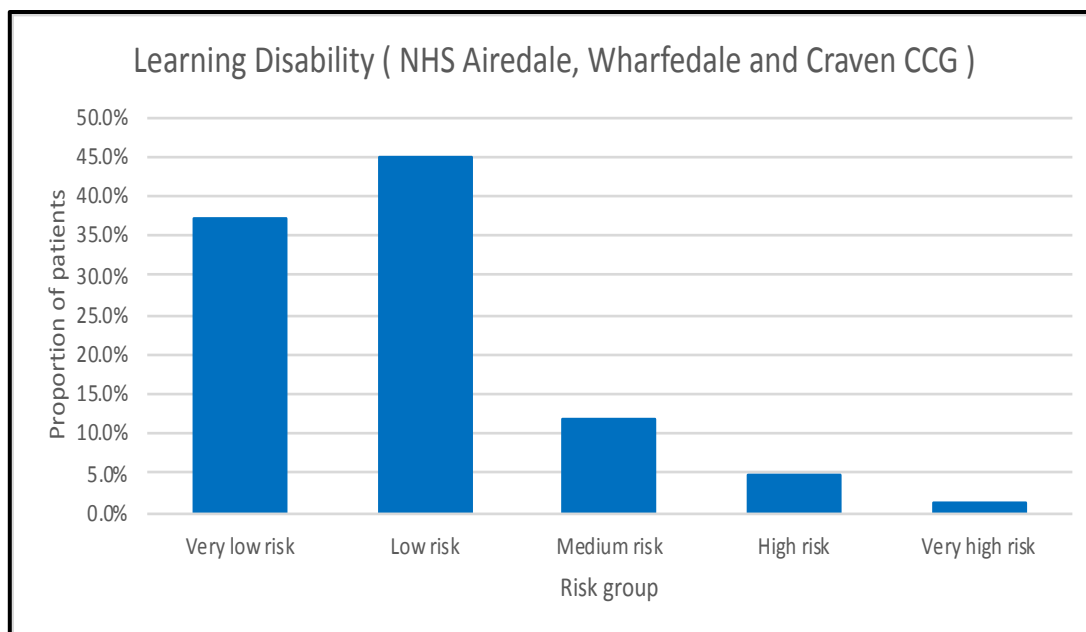
Table 1 Risk of Emergency Admission to Hospital for People with Learning Disabilities,

Airedale Wharfedale & Craven CCG 2017

CCG	Risk Group	Number of patients	Proportion of patients
NHS Airedale, Wharfedale and Craven CCG	Very low risk	197	37.2%
NHS Airedale, Wharfedale and Craven CCG	Low risk	238	45.0%
NHS Airedale, Wharfedale and Craven CCG	Medium risk	62	11.7%
NHS Airedale, Wharfedale and Craven CCG	High risk	26	4.9%
NHS Airedale, Wharfedale and Craven CCG	Very high risk	6	1.1%
NHS Airedale, Wharfedale and Craven CCG	Total population	529	100.0%

Source: Dr Foster

Figure 1   Risk of Emergency Admission to Hospital for People with Learning Disabilities Airedale Wharfedale & Craven CCG 2017

Source: Dr Foster

Table 2   Risk of Emergency Admission to Hospital for People with Learning Disabilities,
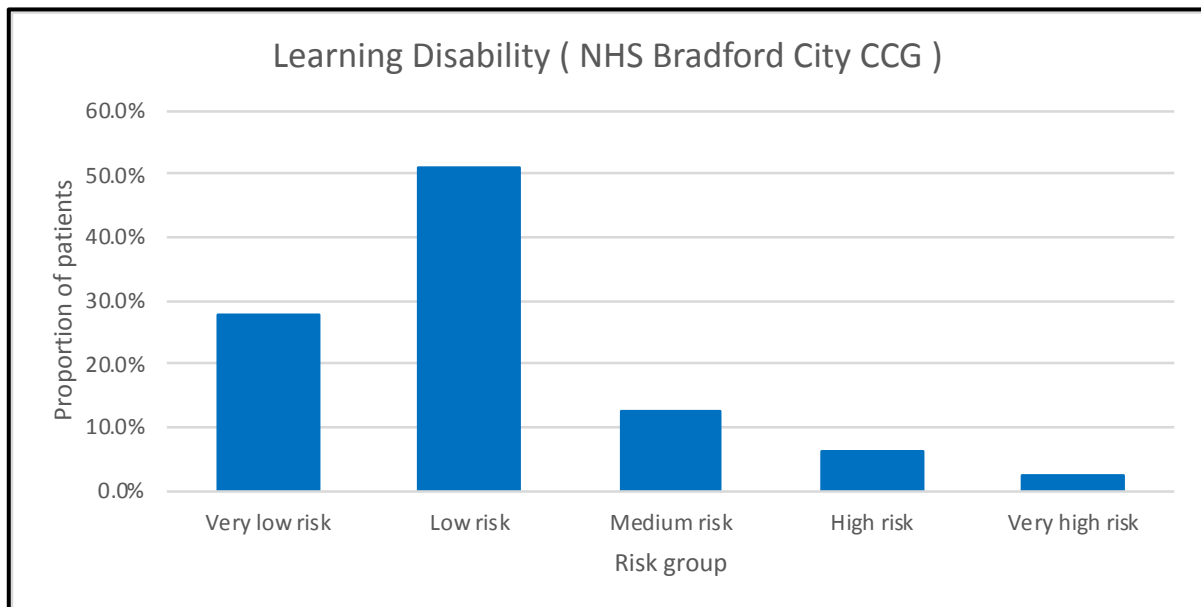
Bradford City CCG 2017

CCG	Risk Group	Number of patients	Proportion of patients
NHS Bradford City CCG	Very low risk	241	27.9%
NHS Bradford City CCG	Low risk	442	51.2%
NHS Bradford City CCG	Medium risk	107	12.4%
NHS Bradford City CCG	High risk	52	6.0%
NHS Bradford City CCG	Very high risk	22	2.5%
NHS Bradford City CCG	Total population	864	100.0%

Source: Dr Foster

Figure 2 Risk of Emergency Admission to Hospital for People with Learning Disabilities,

Bradford City CCG 2017

Learning Disability (NHS Bradford City CCG)

Source: Dr Foster

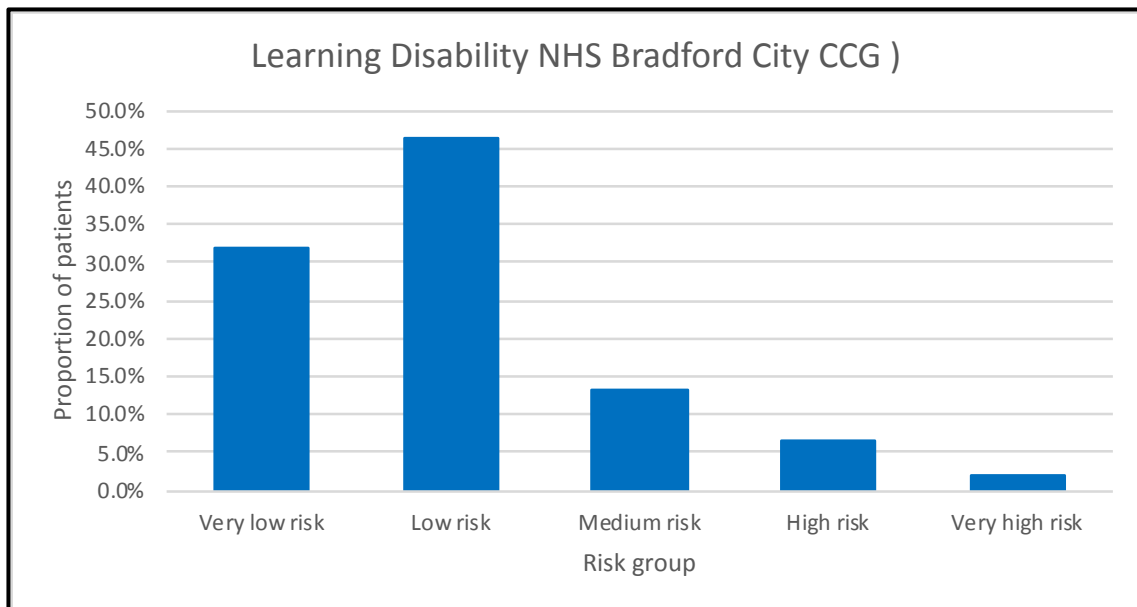**Table 3   Risk of Emergency Admission to Hospital for People with Learning Disabilities,**

Bradford Districts CCG 2017

CCG	Risk Group	Number of patients	Proportion of patients
NHS Bradford Districts CCG	Very low risk	636	31.8%
NHS Bradford Districts CCG	Low risk	928	46.4%
NHS Bradford Districts CCG	Medium risk	265	13.3%
NHS Bradford Districts CCG	High risk	133	6.7%
NHS Bradford Districts CCG	Very high risk	38	1.9%
NHS Bradford Districts CCG	Total population	2000	100.0%

Source: Dr Foster

Figure 3   Risk of Emergency Admission to Hospital for People with Learning Disabilities

Bradford Districts, CCG 2017

Source: Dr Foster

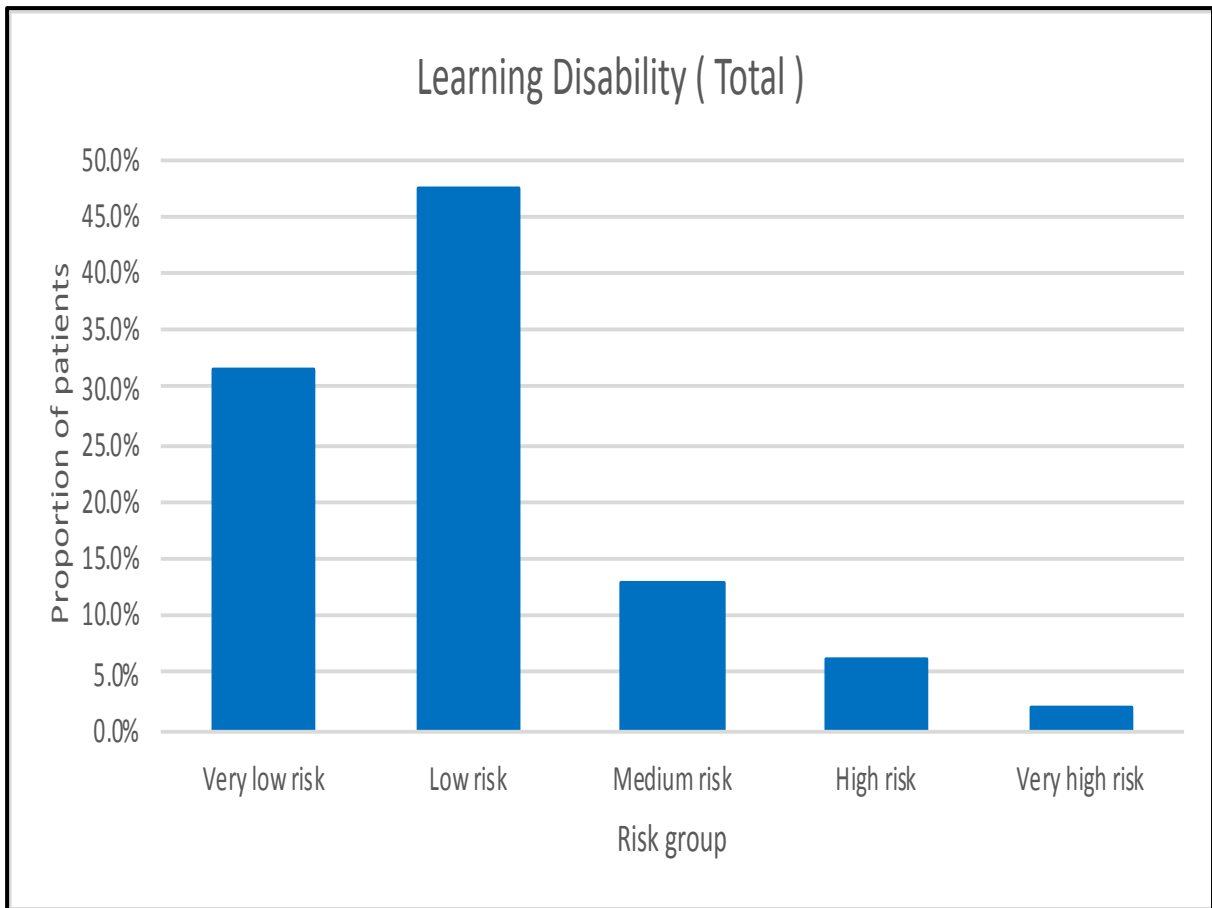**Table 4   Risk of Emergency Admission to Hospital for People with Learning Disabilities**

Bradford 2017

Area	Risk Group	Number of patients	Proportion of patients
Bradford District	Very low risk	1074	31.7%
Bradford District	Low risk	1608	47.4%
Bradford District	Medium risk	434	12.8%
Bradford District	High risk	211	6.2%
Bradford District	Very high risk	66	1.9%
Bradford District	Total population	3393	100.0%

Source: Dr Foster

Figure 4   Risk of Emergency Admission to Hospital for People with Learning Disabilities

Bradford 2017

Source: Dr Foster

Airedale General Hospital

This section, through Tables 5 to 8 and Figures 5 to 9 below, sets out the pattern of admission to Airedale General Hospital from August 2017 to July 2018 for people with a Learning Disability

Summary:

- **170** individuals with a learning disabilities flag on SystmOne were admitted **318** times
- **58%** of these 318 admissions were emergency and **36%** were planned elective.
- 64% (109) were only admitted once in the 12 mths
- **5% (9) were admitted 5 or more times**
- 46% of admissions were to Wards 2, 17 or 20. (Acute Medical Unit, Paediatric, Day)
- 50% were admitted under General Medicine, Paediatrics or General Surgery
- **58% of admissions did not stay overnight**
- **13% stayed 5 or more nights**
- 53% of admissions were female
- 24% were aged under 20 and 18% were aged 60+yrs.

Table 5   Admissions by Ward, People with Learning Disabilities, Airedale Hospital,   August 2017 to July 2018

Admitting Ward	Total	%
Ward 2	56	17.61%
Ward 20	46	14.47%
Ward 17	45	14.15%
Acute Assesssment Unit	27	8.49%
HODU	27	8.49%
Ambulatory Care Unit	24	7.55%
Endoscopy Unit	21	6.60%
Surgical Assessment Unit (now AAU)	14	4.40%
Labour Suite	14	4.40%
Ward 14	9	2.83%
Early Pregnancy Assessment Unit	8	2.52%
Critical Care	5	1.57%
Dales Suite	5	1.57%
Ward 21	<5	1.26%
Ward 9	<5	0.94%
Ward 13	<5	0.94%
Unknown	<5	0.63%
Cardiology Day Case Unit	<5	0.63%
Max Fax Suite	<5	0.63%
Ward 5	<5	0.31%
Total	**318**	**100.00%**

Table 6   **Admissions by Type of Admission, People with Learning Disabilities, Airedale General Hospital, August 2017 to August 2018**

	Elective	Emergency	Non-Elective	Total
Number	115	184	19	318
%	36%	58%	6%	100%

Figure 5   **Admissions by Type of Admission, People with Learning Disabilities, Airedale General Hospital, August 2017 to August 2018**
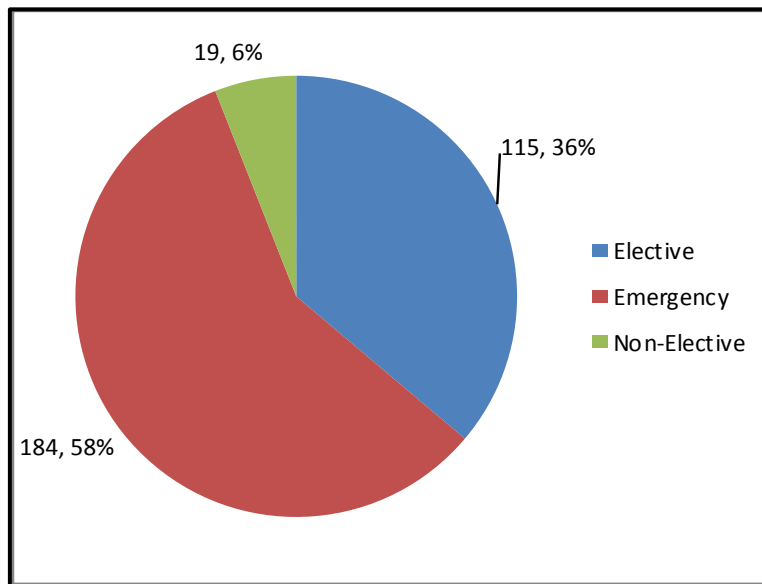

Figure 6   **Length of Stay, Admissions for People with Learning Disabilities, Airedale General Hospital, August 2017 to August 2018**

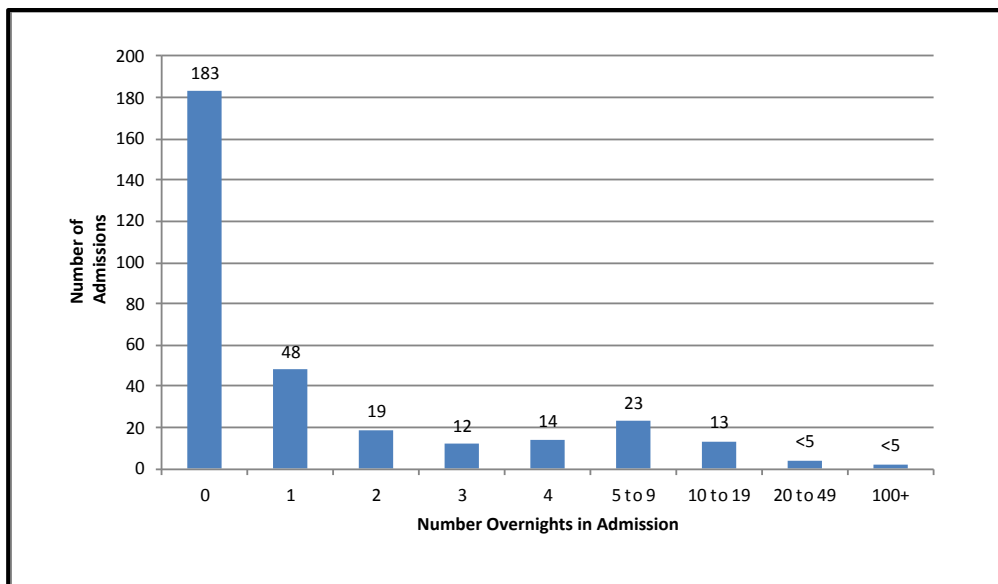**Table 8   Admission by Specialty, People with Learning Disabilities, Airedale General Hospital, August 2017 to July 2018**

Admitting Specialty	%
General Medicine	29%
Paediatrics	11%
General Surgery	10%
Urology	9%
Clinical Haematology	8%
Gastroenterology	6%
Obstetrics	5%
Gynaecology	5%
Trauma & Orthopaedics	4%
Oral Surgery	3%
Dental Medicine Specialties	3%
Respiratory Medicine	2%
Geriatric Medicine	2%
Ophthalmology	1%
Cardiology	1%
Endocrinology	0%
Stroke Medicine	0%
Paediatric Trauma And Orthopaedics	0%
Total	**100%**

Figure 7   Admissions per Patient, People with Learning Disabilities, Airedale General Hospital, August 2017 to July 2018
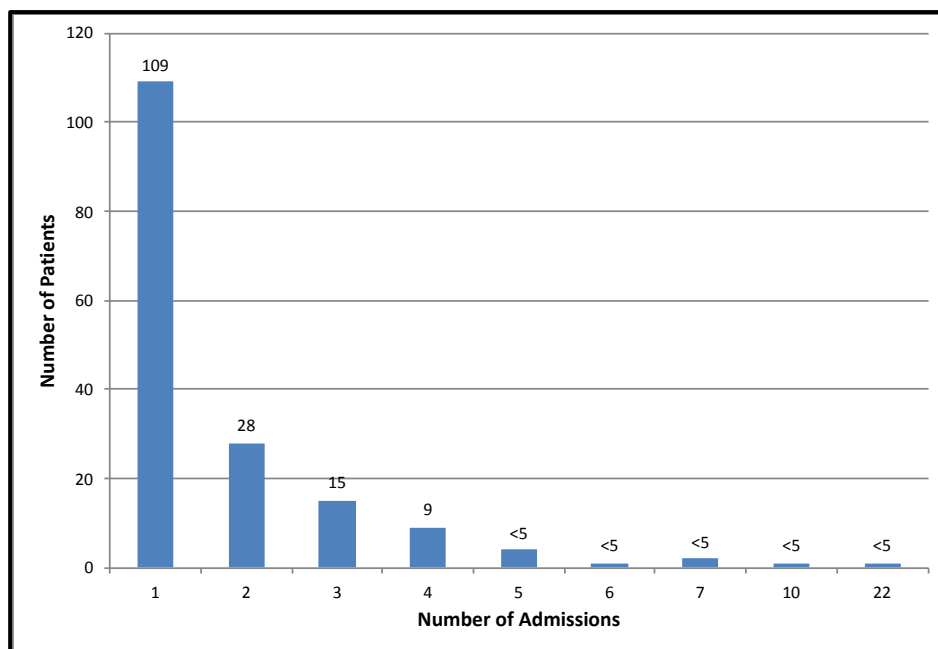
Figure 8   Admissions by Gender, People with Learning Disabilities, Airedale General Hospital, August 2017 to July 2018
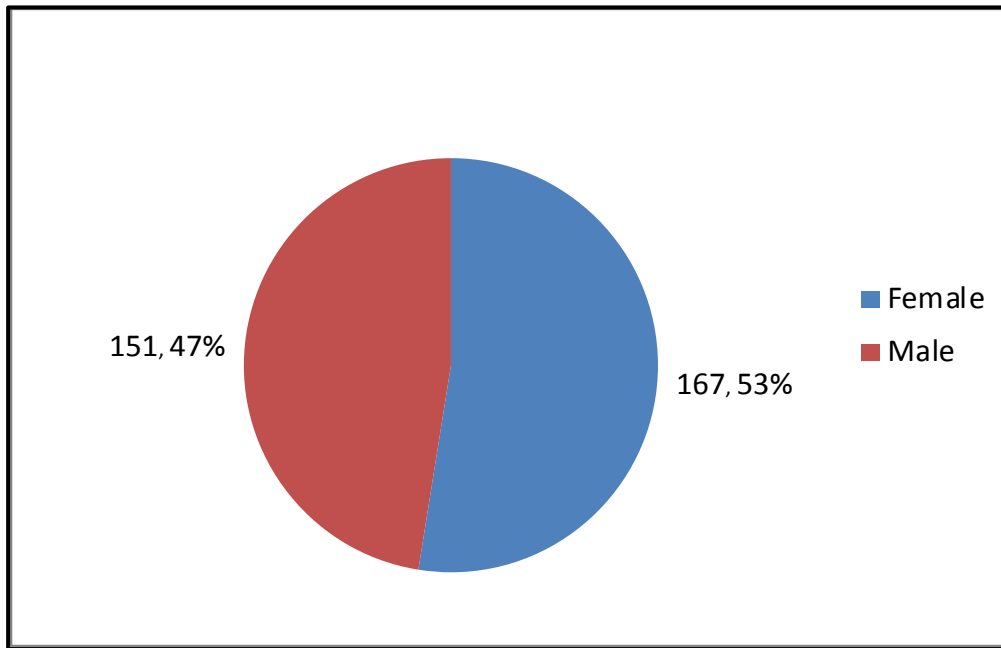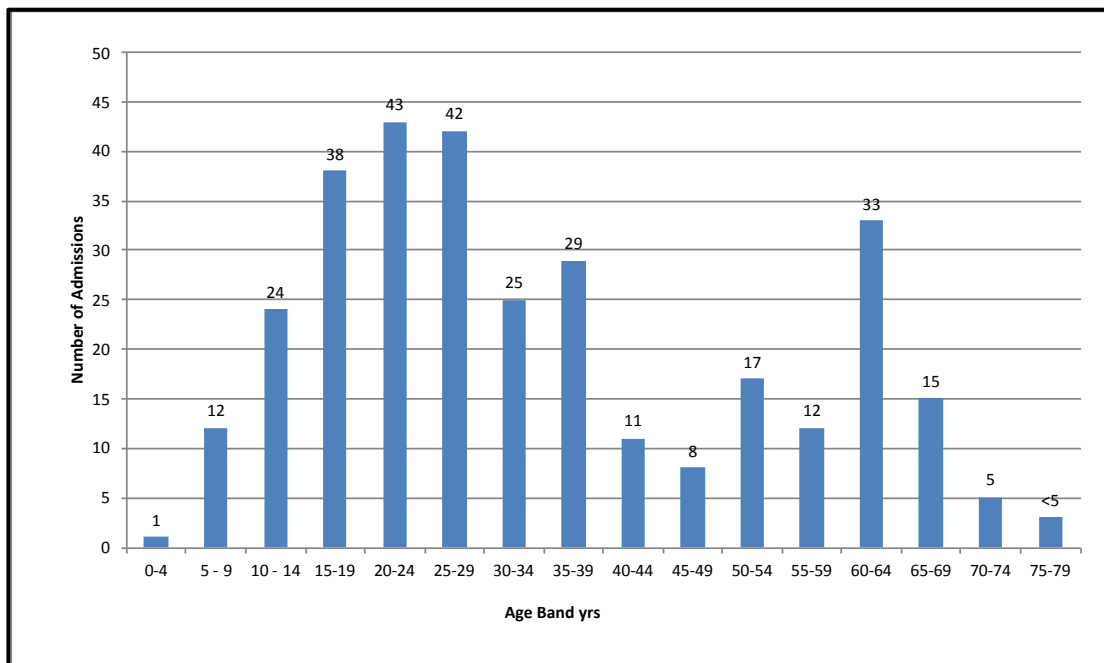

Figure 9   Admissions by Age Band, People with Learning Disabilities, Airedale General Hospital, August 2017 to July 2018

Note - Bradford Royal Infirmary

Figures from Bradford Royal Infirmary (BRI) are currently being collected and will be added to the report as soon as they are available.

Bradford District Care Trust

Bradford District Care Trust (BDCT) provides mental health, community and learning disability services that look after the 'whole person', caring for their physical and mental health needs. BDCT works with individuals, their carers and our partners to ensure that people get the right care, in the right place with the right support.

In respect of Learning Disabilities and Autism, there are three main service areas

1. The Learning Disability Health Support Team.

The Health Support Team works from Bradford (<u>Waddiloves Health Centre</u>), Keighley (<u>The Oaks</u>) and Skipton and works with adults with Learning Disabilities who have physical health needs mental health needs. The Health Support Team can offer support when needs cannot be met by mainstream services.

2. The Health Facilitation Team

A range of health professionals and health support workers work in the health facilitation team. These include:

- Dietitians who can help a person plan a healthy diet
- Occupational therapists who can support a person to be actively involved in every aspect of their life - they may assess a person's skills and suggest equipment or approaches that may help.
- Psychiatrists who can support a person who has mental illness
- Psychologists who can help people with LD and their carers to understand feelings and behaviour, and support them to feel better and do things differently.
- Learning disability nursees who help people get their physical, mental and emotional needs met when they need extra support with these. They work with the person, carers, GP, hospital or other health provider to ensure people get reasonable adjustments made to access the right health care.
- Health support workers who work closely with the other people in the team and support people to access lots of different areas of their health, such as getting to appointments, working in physio clinics, making health plans easier to understand or doing desensitisation work.
- Speech and language therapists who can support people with their communication. They can find ways to help people understand information, and ways to help them express themselves. Speech and language therapists can also help with difficulties swallowing, eating or drinking.
- Physiotherapists – to help people walk, breathe better, sleep and find ways to help people sit, sleep or mobilise using hydrotherapy or rebound to support mobility.

3. Specialist Clinics

Specialist clinics are held at Waddiloves Health Centre, if an adult with learning disabilities cannot come to clinic, the specialist team may be able to offer an appointment as a home visit.

- Podiatry clinics identify any foot problems and support people to keep their feet healthy.
- Dental clinics identify any problems with teeth, and support people to keep their teeth healthy.
- Ophthalmology clinics identify any problems with vision, and will help people keep their eyes healthy.
- Audiology clinics identify any problems with hearing and support people to keep their ears healthy.

The Assessment and Treatment Unit at Lynfield Mount Hospital

There is one specialist assessment and treatment ward for adults over 18 with moderate to severe learning disabilities and mental health problems whose needs cannot be supported at home, in the community or in other adult mental health wards. A multidisciplinary team can support people to meet daily living needs and maintain independent skills. The team can ensure that care is personalised and that people with LD are involved in developing their care plan.

Waddiloves Health Centre

In order to provide context to this section, statistics from Waddiloves Health Centre are presented here. This illustrates the service activity and clinical epidemiology of community based services for people with Learning Disabilities and Autism in Bradford who need more reasonable adjustments making than mainstream services can provide.

Note – referral figures presented are on top of caseloads already in place, e.g. CPA care co-ordination role, community matron, CHC caseload etc.

Reason for Referral

Table 9 below sets out the reasons for referral for patients referred to Waddiloves from **Jan to Dec 2017**. As can be seen, the large majority of referrals are for Behavioural or Physical Health reasons. Interestingly, there are a small number referred for Dementia which highlights the emergence of a significant cohort which is likely to expand further as people with both Dementia and Learning Disabilities live longer lives. Table 10 further breaks these referral figures down by accommodation status. Many of the individual figures are concealed to protect anonymity. The large majority are living either in the Family Home or in Nursing Home care Small numbers are living in Residential Homes and Supported Living Accommodation, but only 7 are living independently. The largest single cohorts are:

1. Physical Health Problem living in Family Home – 49 **(26.2%)**
2. Physical Health Problem living in Supported Accommodation – 31 **(16.6%)**
3. Behavioural Problem living in Family Home – 30 **(16%)**

Table 9   Reason for Referral to Waddiloves Health Centre, Jan to Dec 2017

Referral Reason	Total
Behavioural	54
Degenerative Condition	<5
Dementia	9
Mental Health	9
Other	<5
Physical Health	112
Grand Total	187

Table 10 Reason for Referral to Waddiloves Health Centre, by Accommodation Status, Jan to Dec 2017

Accomodation Type	Referral Reason						
	Behavioural	Degenerative Condition	Dementia	Mental Health	Other	Physical Health	Total
Family Home	30	<5	<5	<5	<5	49	79
Living Independently	<5	<5	<5	<5	<5	7	7
Nursing Home	<5	<5	<5	<5	<5	6	86
Other	<5	<5	<5	<5	<5	<5	0
Residential Home	5	<5	<5	<5	<5	14	19
Supported Accomodation	17	<5	<5	<5	<5	31	19
Total	54	<5	5	9	<5	111	179

<u>Where People Live</u>

Research suggests that social exclusion is a problem both for people with LD and for people living in rural areas. This may give rise to a double disadvantage for people with LD living in rural areas. Conversely, aspects of rural life such as community spirit and social support may protect against social exclusion in this population. Interestingly, a 2013 study carried out in Scotland found that adults with LD living in rural areas have better. Opportunities and live in less deprived areas than adults with LD living in urban areas. However, they may not hold such positive or close relationships, and this may be important when considering the subjective experience of social exclusion [6].

Table 11 below sets out referrals to Waddiloves Health Centre by where the people referred live. Not surprisingly the majority of referrals come from the more densely populated areas of the Keighley, City and District Localities.

Table 11   Referrals to Waddiloves Health Centre,   by Where People Live, Jan to Dec 2017

Locality	Number
City	50
Craven	<5
District	69
IST	13
Keighley	82
TOTAL	182

Table 12 below subdivides the Locality referral numbers by Accommodation Status. The largest single cohorts are:
1. Family Home in City Locality – 40 **(22%)**
2. Supported Accommodation in District Locality – 34 **(18.7%)**
3. Family Home in District Locality – 26 **(14.3%)**

Table 12   Accommodation Status by Where People Live, Referrals to Waddiloves Health Centre, Jan to Dec 2017

Locality	Accomodation						
	Family Home	Living Independently	Nursing Home	Other	Residential Home	Supported Accomodation	Grand Total
City	40	<5	<5	<5	<5	10	50
Craven	<5	<5	<5	<5	<5	<5	<5
District	26	<5	<5	<5	9	34	69
IST	7	<5	<5	0	<5	6	13
Keighley	15	<5	<5	0	<5	7	82
Grand Total	88	8	2	6	21	57	182

Waddiloves Health Centre Clinic Activity

Table 13 below provides a picture of the day to day caseload at Waddiloves Health Centre, detailing clinic activity for May – July 2018. Separate sections are provided in this report on Dentistry and Dietetic support given the importance of swallowing and airway management tin the care of people with Learning Disabilities.

Table 13   Waddiloves Health Centre Clinical Activity, May-July 2018

Clinical Activity	Number
Audiology	9
Dental	9
ECG in Antipsychotic Prescribing	12
Blood Tests	29
Admissions to BRI -other	9
Pre-op Support	18
Nurse Hearing Test	28
TOTAL	**114**

What Does This Mean for People with Learning Disabilities and Autism in Bradford?

Clearly emergency admission to secondary care is a negative outcome for anyone with LD or Autism. It is encouraging that all three CCG populations show the largest cohorts as those with a lower risk of emergency admission. However, there remain a number of patients with multiple admissions and extended periods of stay, although again it is encouraging that 58% of admissions to Airedale General Hospital did not stay overnight. The Waddiloves centre is clearly an important hub for people with LD and Autism, and it is notable that the largest group of people they manage are those with physical health problems

Strategic Recommendations

1.Focused work should continue across health and social care to identify and prevent multiple hospital admissions in those at high risk

2.Physical health prevention services should be prioritised in community and secondary care services

3. The Hub model seen at Waddiloves should be developed to increase its capabilities as a multidisciplinary focus for health and social care provision

REFERENCES:

1. NHS England, Public Health England, Health Education England, Monitor, Care Quality Commission, NHS Trust Development Authority Five Year Forward View. http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf (accessed 12th Jan 2019)

2. Sheehan, R. et al., 2016. An audit of the quality of inpatient care for adults with learning disability in the UK. BMJ Open, 6(4), p.e010480.

3. Leslie, P., Crawford, H. & Wilkinson, H., 2009. People with a learning disability and dysphagia: a cinderella population? Dysphagia, 24(1), pp.103–104.

4. Chadwick, D.D. & Jolliffe, J., 2009. A descriptive investigation of dysphagia in adults with intellectual disabilities. Journal of intellectual disability research : JIDR, 53(1), pp.29–43.

5. Glover G, Evison F. Hospital Admissions That Should Not Happen, Admissions for Ambulatory Care Sensitive Conditions for People with Learning Disabilities in England. Learning Disabilities Observatory. 2013.

6. Nicholson, L. & Cooper, S.A., 2013. Social exclusion and people with intellectual disabilities: a rural-urban comparison. Journal of intellectual disability research : JIDR, 57(4), pp.333–346.

Section 6 - Social Care

Note – This section is designed to provide only an overview of social care from a strategic standpoint, detailed sections on services such as accommodation, education and employment are contained within their own sections of this report

In adult services, the support offered to people with LD and Autism is decided through a **needs assessment**, carried out by CBMDC. What is needed in terms of care and support, healthcare and housing should all be considered as part of this assessment. Every Local Authority has a legal duty to carry out an assessment if it appears a person needs social care services. There should be a low threshold to trigger the duty to carry out an assessment – the Local Authority should investigate whether there is any realistic prospect that services may be needed, and if so, an assessment should be carried out. Once the Local Authority has carried out an assessment, it will need to determine which needs are eligible for support. In order to do this, the Local Authority will refer to its eligibility criteria.

Predicting Social Care Need for People with Learning Disabilities

A study carried out by the National Institute for Health Research in 2012 undertook modelling that suggested sustained growth in the need for social care services for adults with learning disabilities over the time period 2012–30 [1]. Key findings included:
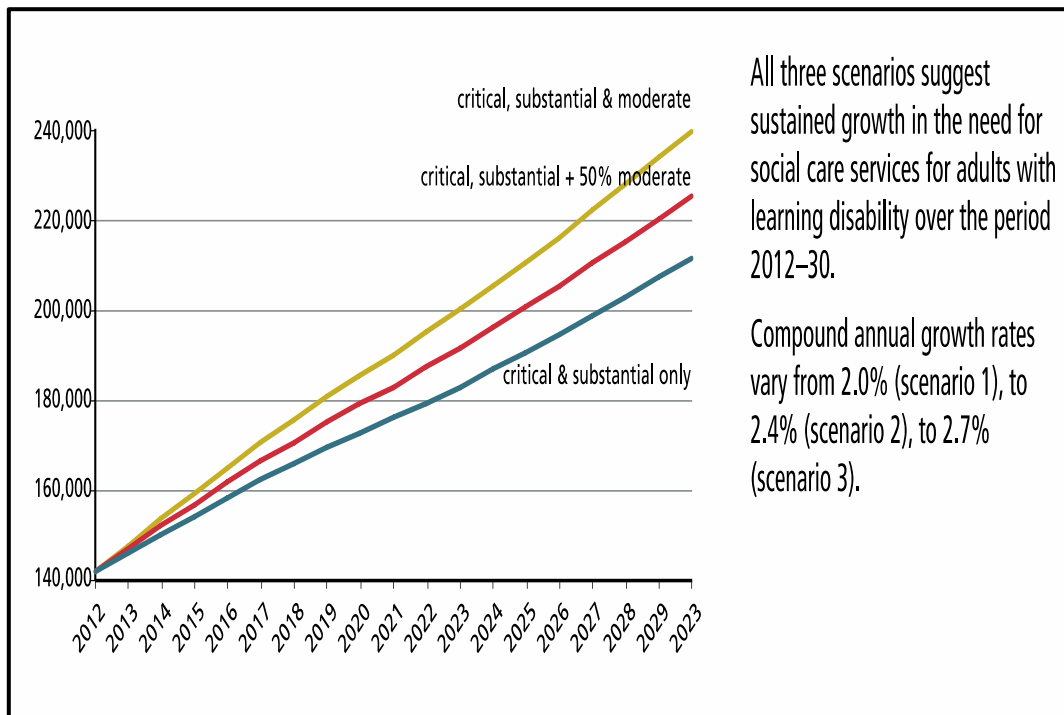
- For adults with learning disabilities, **annual growth rates** in the number of users of adult social care varied from **2.0%** to **2.7%** depending on assumptions. These estimates would involve providing support to between an additional **37,000** to **52,000** adults with learning disabilities over the next ten years (equating to roughly **370** to **520** in Bradford).
- A 'no growth' scenario in the number of users of adult social care services for people with learning disabilities could only be achieved by either deeming some current users as ineligible for social care services or by rationing access to services to young people with learning disabilities with 'critical' need and 25% of those with substantial need.

The authors also pointed out that:

- At a national level any net effects of international migration are likely to be minimal, however effects may be of local importance in areas with **high concentrations of refugee children**.
- Although some factors are likely to lead to an increase in prevalence of LD (e.g. increases in maternal age, improved survival of 'at risk' infants) and some to a decrease (e.g. more prenatal screening for Down's syndrome, fewer 'at risk' infants developing disabilities), the research team considered it unlikely that the net effect would have a significant impact.

- Current trends suggest mortality rates in people with LD should continue to fall, but precise predictions are not possible. However, any error here would only lead to a marginal underestimate of future need.

Figure 1   Predicted Changes in Social Care Need, England 2012-2023

Source: National Institute for Health Research

Funding Predicted Adult Social Care Need

An analysis undertaken by the Health Foundation in 2018 [2] used financial modelling, public perceptions work and policy analysis to identify current problems with adult social care in England and outlined some options for its reform based on:

1. A Cap and Floor payment system
2. Free Personal Care

The report found that **additional revenue will need to be raised for adult social care services even without a major change in the model of delivery.** Social care is facing high growth in demand and cost, which is projected to rise by around £12bn by 2030/31. At the same time, there is project growth in spending on social care of just 2.1% a year in the face of a projected 3.7% rise in need. This would leave a funding gap of £1.5bn in 2020/21 and £6bn by 2030/31, at current prices. Table 1 below sets out the modelled national cost under the current system and the proposed reforms.

Table 1 Costs of Alternative Models for Social Care Funding in England

		Current System		Reforms	
		Maintaining at 2015/16 levels	**Restoring to 2009/10 levels**	**Cap and floor 1**	**Free personal care**
2020/21	**Projected cost pressures**	£21bn	£27bn	£25bn	£26bn
	Increase from 2015/16 spend of £17.1bn	£4bn	£10bn	£8bn	£9bn
	Additional cost above maintaining 2015/16	N/A	£6bn	£4bn	£6bn
	Projected funding available	£19bn			
	Extra funding required	**£1.5bn**	**£8bn**	**£5bn**	**£7bn**
2030/31	**Projected cost pressures**	£29bn	£39bn	£35bn	£37bn
	Increase from 2015/16 spend of £17.1bn	£12bn	£22bn	£18bn	£20bn
	Additional cost above maintaining 2015/16	N/A	£9bn	£6bn	£8bn
	Projected funding available	£23bn			
	Extra funding required	**£6bn**	**£15bn**	**£12bn**	**£14bn**

* A cap of £75,000 and a floor of £100,000. The actual level of the cap has not been specified and costs will depend greatly on this. Source: Health Foundation/Nuffield Trust

Social Care for People with Autism

People with Autism can experience particular difficulties in accessing social care, due to factors relating both to their condition and to the social care system as it stands. A study carried out by the Social Care Institute for Excellence found that [3]:

- Lack of understanding of ASC and of related skills and knowledge is pervasive, among both social care and health professionals, compounded by ASC being a spectrum of conditions and not one homogeneous picture.
- **Autism-specific services** may help, but more important is a better understanding of the needs of people with ASC by a wide range of staff.
- **Access to a diagnosis** of ASC is a major issue in a context where diagnosis or a label of some kind is essential to access services, and assessment for personalisation appears unlikely to take place without it.
- The struggle to be **accepted as eligible** for services is another compelling story. Service providers thought the personalisation agenda would result in fewer choices being available, particularly in the context of costly specialist residential services.
- Concerns about lack of suitable services were strongly expressed, and the related lack of understanding of ASC shown by many social care and health professionals was strongly expressed. This concern extends to non-professionals who occupy important roles gatekeeping services, such as people on the front desk or reception services.
- Falling between services and being passed around services are major issues. Most often this is about falling between social care, particularly learning disability services, and mental health services; and it is also about falling into inappropriate services in order to try and access services.
- The practical barriers to access, including communication barriers, emerged as significant, as these act as barriers to accessing assessments of all kinds, including routine medical and dental examinations and treatment.

Social Care in Bradford

(Note – Accommodation, Education and Transition, Employment and Safeguarding are addressed in separate sections of this report)

Access to Social Care

Table 2 below shows overview figures for provision of social care for adults with LD in Bradford in 2016, comparing with regional and national figures. The figures show that Bradford provides long term LD support to just under half of the people on our GP LD register (1,670 people), a lower figure than the national and regional figures. This may demonstrate poorer access to care in Bradford than regionally and nationally.

Table 2   Overview of Social Care Provision for People with LD, Bradford 2016

!ndicator	Period	Bradford		Yorkshire and Humber	England		
		Count	Value	Value	Value	Lowest	Highest
% of supported adults with learning disability receiving direct payments	2015/16	430	25.70%	28.40%	28.60%	4.40%	84.30%
Adults receiving long term LD support from LA per 100 people on GP learning disabilities register	2015/16	1,670	47.9	53.5	54.5	32	100.2

Direct Payments

"Direct payments" are cash payments given directly to the person who needs care and support (or their family if the person lacks the capacity to manage their money themselves) so that they can choose what services to buy and organise their own support. This is an alternative to services being provided directly by the local authority or by another organisation like a charity. The idea is that disabled people and their families will have more choice and control over their own care by using direct payments. This can mean employing carers directly. It is reasonable to view direct payments as a proxy measurement for independent living and thus a positive measure.

Table 2 above shows the proportion of people with LD accessing direct payments in Bradford compared with regionally and nationally. As can be seen, just over a quarter of adults in Bradford access direct payments, slightly lower than the regional and national figures.

Commissioned Activity

Depending on their support needs, activities to support people with a LD and Autism focus on increasing employment opportunities, getting people into settled accommodation, and giving them access to healthcare. Additionally there is a need to provide for the national plan to reduce the number of beds for people with a learning disability in mental health hospitals by 35% to 50%.

Table 2 below sets out the range of services commissioned by CBMDC to support people with LD and Autism. Services are dominated by Day Care, Supported Living, Direct Payments and Home Care.

Table 2   Social Care Activity for People with LD and Autism, Bradford, December 2018

Service	Number of Recipients
Day Care	1,254
Direct Payments	476
Homecare	446
Individual Service Fund	19
Nursing	48
Residential	173
Support at Care Home	<5
Support at Day Care	64
Supported Living	857
TOTAL	3,340

What Does This Mean for People with Learning Disabilities and Autism in Bradford?

Social care forms the cornerstone of support in day to day living for people with LD and Autism. The range of services available is broad and the system itself can be complex to navigate, both for service users and for those who provide it. Our figures for proportion of people with LD who access social services are low compared with regional and national figures – this could be both a good or bad observation.

It is clear that Direct Payments are a crucial basis for independence and there is scope to increase access to them and to match regional and national figures.

Strategic Recommendations
1. A Programme approach should be taken to simplifying and clarifying the social care system in Bradford, both for those who access the services and those who provide them
2. Council-wide Support should be provided to teams who are undertaking planning for future provision of social services

---

REFERENCES:

1. Emerson E, Robertson J, Coles B, Hatton C (2012) Estimating the Need for Social Care Services for Adults with Disabilities in England 2012–2030. Lancaster: CeDR.
2. Bottery S, Varrow M. A fork in the road: Next steps for social care funding reform. The costs of social care funding options, public attitudes to them – and the implications for policy reform. Health Foundation. 2018.
3. Access to social care for adults with autistic spectrum conditions. Social Care Institute for Excellence. Updated Jan 2017.

Section 7 - Safeguarding

Unfortunately, when considering the care of people with LD and Autism, we must include the prevention and detection of abuse, violence and neglect. Many studies demonstrate that individuals with LD and Autism are at a much higher level of risk than their peers [1]. This applies to both LD and Autism - autistic people may be at higher risk of being abused than other people. It can also be more difficult to detect they are being abused. This may be because autistic people can have limited speech, struggle to communicate and find it difficult to identify their emotions. They may also demonstrate that they are being abused by a change in behaviour. Children who have LD and Autism are at an increased risk of being abused compared with their non-disabled peers [2]. They are also less likely to receive the protection and support they need when they have been abused [3]. An adult at risk is a person aged 18 or over who has needs for care and support (whether or not the local authority is meeting any of those care and support needs), and as a result of those care and support needs is unable to protect themselves from either the risk of, or the experience of abuse or neglect.

People with learning disabilities are more likely to be victims and perpetrators of crime (Nixon et al., 2017). Those with a learning disability are amongst the most vulnerable within society and the safety of people with learning disabilities is of paramount importance. Due to the nature of learning disabilities, many face the risk of exploitation and abuse, ranging from physical, sexual, financial to neglect. Children with learning disabilities are the highest risk group for sexual abuse. Vulnerable children with a learning disability have been known to become involved in sexual abuse both as a victim and as a perpetrator.

The Care Act statutory guidance defines adult safeguarding as [4]:

'Protecting an adult's right to live in safety, free from abuse and neglect. It is about people and organisations working together to prevent and stop both the risks and experience of abuse or neglect, while at the same time making sure that the adult's wellbeing is promoted including, where appropriate, having regard to their views, wishes, feelings and beliefs in deciding on any action. This must recognise that adults sometimes have complex interpersonal relationships and may be ambivalent, unclear or unrealistic about their personal circumstances.'

As a statutory function, A Local Authority must make (or cause others to make) any enquiries it deems appropriate, and hence act, when it has 'reasonable cause to suspect that an adult in its area (whether or not ordinarily resident there):
- Has needs for care and support (whether or not the authority is meeting any of those needs),

- Is experiencing, or is at risk of, abuse or neglect, and
- As a result of those needs is unable to protect himself or herself against the abuse or neglect or the risk of it.' (Care Act 2014, section 42 [4])

In respect of this report, we are concerned with safeguarding for adults and children with LD or Autism, with or without mental and/or physical illness, who have care and support needs that may make them more vulnerable to abuse or neglect.

Risk factors for abuse in vulnerable adults

Certain personal characteristics of adults at risk can increase their vulnerability, and thus susceptibility to abuse. A lack of mental capacity to make decisions about their own safety can place individuals at risk. Those who are unable to make such decisions have impaired ability to protect themselves from bad decisions and may be impaired in asking for help if they experience an abusive act. A 2013 BMJ Review sets out key risk factors as [5]:

- Lack of mental capacity
- Being physically dependent on others
- Low self esteem
- Previous history of abuse
- Negative experiences of disclosing abuse
- Social isolation
- Lack of access to health and social services or high quality information

Types of abuse of vulnerable adults

Physical abuse—including hitting; slapping; pushing; kicking; misuse of medication, restraint, or sanctions

Domestic violence or abuse - including; psychological, physical, sexual, financial and emotional.

Sexual abuse—including rape and sexual assault or sexual acts to which the adult at risk has not consented, could not consent, or was pressured into consenting

Psychological abuse—including emotional abuse, threats of harm or abandonment, deprivation of contact, humiliation, blaming, controlling, intimidation, coercion, harassment, verbal abuse, isolation or withdrawal from services or supportive networks

Financial or material abuse—including theft; fraud; exploitation; pressure in connection with wills, property, inheritance, or financial transactions; misuse or misappropriation of property, possessions, or benefits

Modern slavery - including human trafficking, forced labour, domestic servitude, sexual exploitation; such as escort work, prostitution and pornography and debt bondage; being forced to work to pay off debts that realistically they never will be able to

Neglect and acts of omission—including ignoring medical or physical care needs; failure to provide access to appropriate health, social care, or educational services;

the withholding of the necessities of life such as medication, adequate nutrition, and heating

Discriminatory abuse—including racist, sexist, that based on a person's disability, and other forms of harassment, slurs, or similar treatment

Self-neglect – including lack of self-care to an extent that it threatens personal health and safety, neglecting to care for one's personal hygiene, health or surroundings, inability to avoid self-harm, failure to seek help or access services to meet health and social care needs, Inability or unwillingness to manage one's personal affair

Organisational or institutional abuse – including: discouraging visits or the involvement of relatives or friends, run-down or overcrowded establishment, authoritarian management or rigid regimes, lack of leadership and supervision, insufficient staff or high turnover resulting in poor quality care, abusive and disrespectful attitudes towards people using the service

inappropriate use of restraints, lack of respect for dignity and privacy etc.

Safeguarding In Bradford

Governance of the Safeguarding function in Bradford is overseen by a **Safeguarding Adults Board** (SAB) and a **Safeguarding Children's Board** (SCB). Both are statutory, with the SAB statutory as result of the Care Act 2014. The main job of the Safeguarding Boards is to ensure that local safeguarding arrangements work effectively so that those at risk due to health needs, social care needs or disabilities are able to live their lives free of abuse or neglect.

Safeguarding Adults Board

The Safeguarding Adults Board is a multi-agency partnership which has statutory functions under the Care Act 2014. The overarching purpose of an SAB is to help and safeguard adults with care and support needs. It does this by: assuring itself that local safeguarding arrangements are in place as defined by the Care Act 2014 and statutory guidance, assuring itself that safeguarding practice is person-centred and outcome-focused, working collaboratively to prevent abuse and neglect where possible, ensuring agencies and individuals give timely and proportionate responses when abuse or neglect have occurred and assuring itself that safeguarding practice is continuously improving and enhancing the quality of life of adults in its area.

SABs have three core duties:
1. To develop and publish a strategic plan setting out how they will meet their objectives and how their member and partner agencies will contribute
2. To publish an annual report detailing how effective their work has been
3. To commission safeguarding adults reviews (SARs) for any cases which meet the criteria for these.

The Bradford Safeguarding Adults Board is chaired by an Independent Chair and membership to the Board includes representation from the following agencies:
- Bradford Council
- Police
- Clinical Commissioning Groups (CCGs)
- NHS organisations
- Probation
- Fire Services
- Yorkshire Ambulance Services
- Housing
- Independent sector
- Voluntary organisations
- Service user representation

The work of the Safeguarding Adults Board takes forward the key values of Making Safeguarding Personal (MSP). It fully supports the following 6 Principles taken from

Department of Health for England and Wales. Statement of government policy on adult safeguarding [6].

1. Empowerment
2. Prevention
3. Proportionality
4. Protection
5. Partnership
6. Accountability

At the end of each financial year the Board publishes an annual report. The report tells people what work the Board has done over the past twelve months to help keep adults safe.

Safeguarding Activity

Children
Numbers in Care
We are currently caring for **245 children** allocated to staff

- **171** on Direct Payments age 2-18
- **42** on Homecare packages age 9-18

Of these, the vast majority are either British White (**132**) or British/Asian Pakistani (**95**)

Respite Care
In Bradford we have the following:
2 Specialist Short Break Services

- Airedale - Clockhouse in Keighley - **6 beds**
- Bradford - Wedgewood in Holme Wood - **10 beds**
- Bradford – Specialist Residential Home in City area for children who display challenging behaviours with a linked Behavioural Assessment Unit
- Shared Care - service run by Bradford Council offering short breaks to children with complex disabilities and health needs and consists of a team of approved carers

Criteria and age range for access these are the same for all provisions from reception to 18, these being: **LD with any additional complex health needs or ASC diagnosis**.

In addition:

Valley View (residential for when parents cannot cope **2x 50/50 beds** to try and keep people at home) -   Currently caring for **6 children full time**

BEST (provides behavioural support to keep people at home by bringing the patients in and sending having been treated. Currently caring for **7 children full time**

<u>Social Workers</u>
Bradford has a specialist Social Work Team (CCHDT) I have enclosed a summary of services that I copied off the local offer website.

Adults
Data from CBMDC Safeguarding show that:

<u>Year-end information 2018</u>
From the safeguarding adults return it is noted that out of **4,814** concerns raised, **430** identified Learning Disabilities as the primary support reason.

<u>Current year from 1st April to present</u>
There have been **438** concerns raised regarding people with a Learning Disability which breaks down in **439** as adult at risk and **165** as person alleged to have caused harm.
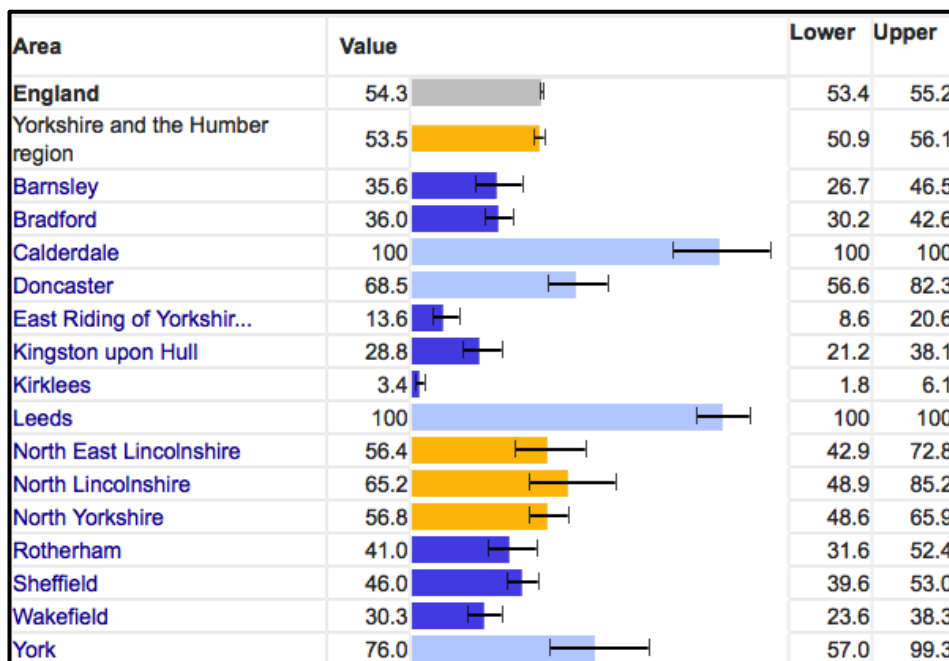
Section 42 Enquiries
Section 42 enquiries are the *mechanism* by which Local Authorities respond when adults with care and support needs in their area are harmed or are at risk of harm. In essence, they are a means by which safeguarding gets carried out. Data have been reported about adult safeguarding activity annually for several years, however the format has changed several times. In the current format, numbers of individuals involved in section 42 adult safeguarding enquiries is the only variable reported for types of client primary support reason. Information presented below shows the number of individuals involved in enquiries per thousand people on GPs learning disability registers. Nationally, the number of adults subject to a section 42 safeguarding enquiry under the Care Act increased by 6% in 2016-17, official figures show. There were 109,145 adults subject to an enquiry in 2016-17, compared with 102,970 the previous year. The majority, 60%, were female and 63% were aged 65 and over. 36% of risks in section 42 enquiries took place in care homes.

Figure 1 and Table 1 below show Section 42 values per 1,000 people on GP LD Registers for all Districts in Yorkshire and the Humber in 2016/17, with national figures presented for comparison. As can be seen, the figure for Bradford is statistically significantly lower than both the regional and national figures and has one of the lowest figures in the region. There was a notable drop in numbers in Bradford from 2016 to 2017 however this may be an isolated reading and further figures for subsequent years are required in order to validate the observation

Figure 1   Individuals with Learning Disabilities Involved in Section 42 Safeguarding

Enquiries per 1,000 people on the GP Learning Disability Register, England 2016/17

Area	Value			Lower	Upper
England	54.3			53.4	55.2
Yorkshire and the Humber region	53.5			50.9	56.1
Barnsley	35.6			26.7	46.5
Bradford	36.0			30.2	42.6
Calderdale	100			100	100
Doncaster	68.5			56.6	82.3
East Riding of Yorkshir...	13.6			8.6	20.6
Kingston upon Hull	28.8			21.2	38.1
Kirklees	3.4			1.8	6.1
Leeds	100			100	100
North East Lincolnshire	56.4			42.9	72.8
North Lincolnshire	65.2			48.9	85.2
North Yorkshire	56.8			48.6	65.9
Rotherham	41.0			31.6	52.4
Sheffield	46.0			39.6	53.0
Wakefield	30.3			23.6	38.3
York	76.0			57.0	99.3

Source: NHS Digital- Safeguarding Adults Collection https://digital.nhs.uk/article/4492/Social-care

Table 1   Individuals with Learning Disabilities Involved in Section 42 Safeguarding

Enquiries per 1,000 people on the GP Learning Disability Register, England 2016/17

	Bradford		Yorkshire and Humber	England
Period	Count	Value	Value	Value
2015/16	205	58.8	34.1	56.2
2016/17	130	36	53.5	54.3

On first inspection, these figures may seem to be as representative of good practice/low level of need in Bradford, however the converse may also be true with a lower figure representing poor reporting.

What Does This Mean for People with Learning Disabilities and Autism in Bradford?

The Winterbourne View scandal laid bare the potential for safeguarding issues to impact on the wellbeing of people with Learning Disabilities and Autism and brought into sharp relief the importance of keeping these people safe. The two Bradford

Safeguarding Boards are the vital hub of this function with oversight of this crucial issue and must be supported and reviewed appropriately.

Our Section 42 figures are significantly lower than national and regional figures. This could be interpreted as due to both lower need for or lower identification of safeguarding issues.

<div style="border:1px solid black;">

Strategic Recommendations

1. Focused work should continue across health and social care to identify safeguarding issues in a timely and effective manner

2. The Adult and Children's Safeguarding Boards should co-operate in respect of Transition services as people move from one to the other

</div>

REFERENCES:

1. Sullivan, P.M. & Knutson, J.F., 2000. Maltreatment and disabilities: a population-based epidemiological study. Child abuse & neglect, 24(10), pp.1257–1273.
2. Jones, L. et al., 2012. Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies. Lancet, 380(9845), pp.899–907.
3. Taylor, J. et al., 2014. Disabled children and child protection in Scotland: An investigation into the relationship between professional practice, child protection and disability. Scottish Government Research Findings No. 127/2014
4. Legislation.gov.uk. (2014). Care Act 2014. [online] Available at: http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted [Accessed 11 Jan. 2019].
5. Boland, B., Burnage, J. & Chowhan, H., 2013. Safeguarding adults at risk of harm. BMJ, 346(may14 2), pp.f2716–f2716.
6. Department of Health. Statement of government policy on adult safeguarding. 2011. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/147310/dh_126770.pdf.pdf.
7. NIXON, M., THOMAS, S. D. M., DAFFERN, M. & OGLOFF, J. R. P. 2017. Estimating the risk of crime and victimisation in people with intellectual disability: a data-linkage study. Soc Psychiatry Psychiatr Epidemiol, 52, 617-626.

Section 8 - Carers

Almost a fifth of the population in England provide unpaid social care for family and friends. More than 2 million of these carers are aged 65 years and older, and 417,000 of those are more than 80 years old. Two-thirds of carers older than 65 years themselves have a health condition or disability. This major group of the UK's elderly are **doubly vulnerable** [1].

The **Care Act** sets out the following **rights for people who care for a disabled adult** [2]:

- A carer will be entitled to an assessment if it appears that they need support. The carer's assessment must establish whether the carer is willing and able to continue providing care to the disabled person they are caring for, what impact this has on the carer's wellbeing, what outcomes the carer wishes in day-to-day life, and whether the carer wishes to access education, training, or recreational activities.
- The carer will have the same rights to an assessment and support as the disabled adult themselves. Therefore, once a carer's assessment has been carried out, the Local Authority will see which of the carer's needs are eligible for support, and will then produce a support plan to meet the carer's needs.
- Local Authorities are under a duty to meet a carer's eligible needs, subject to a financial assessment.

Key Issues

- One of the most pressing concerns we are facing is that the positive observation of **improved life expectancy** for people with a learning disability means that there are an **increasing number who now outlive their parents**. For those currently living with older parents and carers, this has major implications for the future, with the **likelihood that formal services will eventually take over the care role**. A 2013 review of the literature on future planning for adults with a learning disability who live with older parents and carers. The authors concluded that the presence of a plan for the future, **formulated at a time of stability and in advance of any crisis**, may lead to improved outcomes for the next phase of life [3]. Another key challenge identified was the need to reflect the views of black and minority ethnic families and so-called 'hidden' families who are not known to statutory services. A key common thread was identified, that of the quality of the relationships between the families and the professionals who they come into contact with.
- Carers can experience **stigma** in the same way that people with LD and Autism do. A 2012 review of studies examining self-stigma in people with intellectual disability found that both individuals and family carers experience stigma and that this can have a negative impact on psychological wellbeing [4].

- Many of the more disabled **adolescents** can show an exacerbation of difficult behaviour in the teenage years. Physiological changes leading to puberty and the increase in size can also produce psychological changes. Even the most severely disabled adolescent who is unaware of social situations can be reluctant to accept adult authority and still displays a determination not to give in to adult authority [5].
- Other problems for carers may include the fact that immature and inappropriate behaviour in a teenager can also attract more adverse reactions in public than for a small child – inappropriate behaviour tends to be more tolerated in younger children than in adolescents.
- Attempts to confront a young person who is autistic are even less likely to produce useful results. One of the major problems in caring for this group is the deep resistance to change. This needs careful planning at home and school in order to ensure an organised, predictable day with appropriate structure, but which also takes into account the changes in age, interests and attitudes [5].

Position of National Strategy – Valuing People Now [6]

The National Strategy emphasises that t is vital that family carers are recognised and valued as key partners in the delivery of the national strategy, yet many family carers still face difficulties and further action is needed to address these:
- Families from ethnic minorities are at greater risk of isolation;
- Over 29,000 adults in England live with a parent over the age of 70 (Mencap estimate). Many local authorities failto plan for the future with older families
- **People with learning disabilities who are carers** are often invisible to services because of lack of recognition of mutual caring of parents or partners;
- Family carers were not valued as partners by health service professionals, with serious consequences for their family member;
- Many family carers are **unaware of their right to a carers' assessment** or are turning them down because they do not think it will lead to getting the support they need.

A key report from Lancaster University in 2010 highlighted the main **inequalities being faced by families of and carers for people with LD** [7]
- The risk of children being reported by their main carer (usually their mother) to have fair/poor general health is 2.5-4.5 times greater for children with learning disabilities when compared to their non-disabled peers.
- Carers frequently fail to identify sensory impairments, including cerebral visual impairment, among people with learning disabilities that they are supporting.
- Carers generally have a poor knowledge about public health recommendations on dietary intake.
- Responding appropriately to the health inequalities faced by people with learning disabilities in England demands action on several fronts. These

include enhancing the health literacy of people with learning disabilities and of family carers and paid carers/supporters who play a critical role in promoting healthy lifestyles among many people with learning disabilities.

Bradford Integrated Carers' Service

The service is to provide help and support for carers to have a life of their own along with their caring role. This is done by helping carers to discover opportunities for social and leisure activities as well as training, work and education

The service is based in a central location and supported by GP surgeries, dentists and opticians and supports carers to lead a life outside their caring role.

Who is it for?

What is available?

- Support for isolated carers
- Practical carer support
- Carers' assessments will identify the support that can be provided
- Carers information tailored to individual needs and circumstances
- Carers will be told about services for themselves or the person they care for
- Carers will be shown how to plan for emergencies
- An independent advocacy service to address concerns and allow a carer to find ways to access support
- Carers' will be able to share experiences of caring and access breaks, education, training, leisure and employment
- A carers personal budget which provides small one-off payments to carers to promote their own health and well-being
- Supporting professionals and raising carer awareness
- A way for carers' voices to be heard by local decision makers

Who is it for?

Carers of any age who live in or care for someone who lives in the Bradford, Airedale, Wharfedale and Craven areas. However young carers are likely to be referred to specific young carers' services. People who undertake caring as part of their paid employment or their voluntary work for an organisation are not able to access this service.

Engagement Exercise

This year an engagement exercise with carers and key stakeholders from health and social care services was undertaken by CBMDC with a postal survey, focus group discussions and outreach sessions utilised to maximise representation.

Note this was not exclusive to LD and Autism, with <u>10% caring for a person with Autism</u> and <u>8% caring for a person with LD</u>

In total:
- 303 survey responses were received.
- 20 group visits were undertaken
- Outreach sessions - Around 70 people took part in these conversations.
- It was estimated that this engagement approach reached around **450 carers** from across Bradford District and Craven were involved.

Carers Responses:
- A quarter of respondents said they had been unable to access carers' support services. Of those who had accessed support, **half said it met their needs**.
- Two-thirds of people said caring had a **negative impact on their own health**. Over 25% found it hard to access services for their own health and wellbeing.
- **Support groups** where they could get information made a positive difference.
- Carers expressed the importance of being able to maintain good social networks and having someone to talk to about their experiences.
- **Mental wellbeing** is a significant challenge for many carers who report stress, anxiety and depression linked to their caring role.
- Carers from BME communities and some postcode areas reported finding it harder to access support.
- Money and **financial worries** were a commonly occurring theme, particularly challenges with benefits and the assessment process.
- Carers would like better information, a central resource where information is up to date on what's on offer, what, where and when.
- However, it was also suggested support needs to be local, more easily accessible rather than having to travel to a single office covering the whole District.
- **Carers of people with autistic spectrum disorder, learning disability, or mental health difficulties were more likely to report a negative impact on their own health than other groups of carers**.
- Carers of some groups of people were more likely to report being unable to access support: **Autistic Spectrum Disorder (35%)** or **Learning Disability (30%)**.

Stakeholder Responses:
- Identification of carers within primary and secondary health services is patchy and inconsistent - more awareness raising and training is needed.
- The Local Authority access point is aimed at people in crisis and not people needing information or general advice, there needs to be a different

approach to the provision of advice and information as a preventative measure.

- There are some gaps in available information e.g. for parents of young people in transition between children's and adult services, parents of adults with autism and carers supporting people with other condition specific needs.

What Does This Mean for Carers of People with LD or Autism in Bradford?

Given the prevalence figures set out in Section 2 – Epidemiology, it is reasonable to alight on a gross estimate of ~10,000 for the number of people in Bradford with LD and/or Autism. The number of people who are carers for these people is likely to exceed that estimate, possibly in multiples. The Engagement Exercise carried out in 2018 makes it clear that this group of people feel that their responsibilities as carers impact negatively on their own health – this is of particular concern in elderly carers. The fact that they also report poor access to support services doubles down on these concerns. There are clear normative and expressed needs that are not being expressed, and which perpetuate a pernicious health and social inequality.

Strategic Recommendations

1. **People with learning disabilities have the same access to care and support as everyone else in line with the Equality Act 2010**
2. **We should recognise that people with learning disabilities may be carers, but may not see themselves as such, ask if they have caring responsibilities and, if so, offer them a carer's assessment to meet their needs**
3. **We should provide people with learning disabilities and their family members, carers and advocates with accessible, tailored information about health services and how to access health, social care and support services**
4. **Health and social care practitioners should listen to, actively involve and value key members of the person's support network in the planning and delivery of their current and future care and support, if the person agrees to this**

REFERENCES:

1. The Lancet, 2017. Who cares for the carer? Lancet, 389(10071), p.763.

2. Legislation.gov.uk. (2014). Care Act 2014 Available at: http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted[Accessed27.12/18]

3. Disabilities, R.B.B.J.O.L.2013, "I hope he goes first": Exploring determinants of engagement in future planning for adults with a learning disability living with ageing parents. What are the issues?

4. Ali, A. et al., 2012. Self stigma in people with intellectual disabilities and courtesy stigma in family carers: a systematic review. Research in Developmental Disabilities, 33(6), pp.2122–2140.

5. Rich F. Adolescence and learning disability. Dip HE (Nursing) Learning Disability Branch. Birmingham City University. Available at: https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&ved=2ahUKEwij2NDU2cLfAhUE0xoKHQIlCLkQFjABegQIBRAC&url=http%3A%2F%2Fshareville.bcu.ac.uk%2Findex.php%3Fq%3Dsystem%2Ffiles%2Fdocuments%2Fadolescence_and_learning_disability_workbook.pdf&usg=AOvVaw03a9AlNuNE6drjaPWtyH67 (accessed 27/12/18)

6. Department of Health (2009) Valuing People Now: A new three year strategy for people with Learning Disabilities. London: Department of Health

7. Emerson E, Baines S. Health Inequalities & People with Learning Disabilities in the UK: Learning Disability Observatory. 2010.

Section 9 – Economics and Employment

The first national Employment Strategy for people with learning disabilities was completed in 2003, guided by the Valuing People White Paper 2001 which recognised the need for people with learning disabilities to have access work and employment opportunities. Since then significant progress has been made both nationally and locally to improve the chances of people with a learning disability to gain appropriate training and skills to gain employment including paid employment.

Why is Employment Important for People with LD and Autism?

Many studies and reviews have demonstrated the broad health benefits of employment, not least of all on mental health [1]. Studies also show that there are significant benefits for businesses that employ people with a learning disability, including the boosting of staff morale, improving the public image of companies, and financial costs [2]. Equally, it is important to bear in mind that, in advocating for a greater role for people with a learning disability in the workplace we are limited by the **lack of an extensive research literature on the financial costs and benefits to employers of employing people with a learning disability**. Equally, the drive from equality legislation has led to a focus on disability more generally than specifically on people with a learning disability.

Employment in People with Learning Disabilities

In the UK, the numbers of people with a LD who have a job are very low. In 2018 in England around **6%** of people "known to social services" were in paid employment, compared to **48%** for people with other disabilities and **75%** for the general population in the UK. The reason for this very low figure comes from a combination of the personal barriers people with a learning disability face in working, the lack of appropriate support to help them work, and a lack of awareness and aspiration among all stakeholders that they can be valuable workers [3]. The work barriers people face themselves can include [4,5]:

- Slower than average learning of new tasks
- Impaired memory
- Impaired communication impacting on receiving instruction and giving information
- Impaired motor function performance
- Difficulty in changing learned routines

A 2017 systematic review conducted by Mencap reviewed some of the perceived extra costs that can stop organisations from employing people with learning disabilities. They reported that some of the concerns of these organisations include [2]:

- Concerns about the extra supervision and training costs that the employee may need.
- Concerns about the cost of making reasonable adjustments to accommodate someone with a disability.

- Concerns that workers with a learning disability would represent a greater health and safety risk than other workers.

Employment of People with Learning Disabilities in Bradford

Table 1 below sets out the current extent and type of employment in people with LD in Bradford. Clearly the number of people in employment of any weekly duration is extremely small in comparison with the number who are not seeking work. The number seeking work is encouraging but will still struggle to make inroads into the extent of unemployment shown.

Table 1   Extent and Type of Employment in People with LD, Bradford January 2019

Seeking work	**57**
Not seeking work	**1730**
Not known if client is employed	**<5**
Paid Employment - less than 16 hours per week	**59**
Paid Employment - more than 16 hours per week	**13**
TOTAL	**1861**

Table 2 below shows figures from 2015/16 comparing the proportion in Bradford of supported working age adults with LD in paid employment with the figures for Yorkshire and the Humber and England. The count of 80 people is similar to the figure in Table 1 for Jan 2019 (72), but lower than both the national and regional figures. The highest figure of 22% is notable and perhaps suggests a feasible strategic target to be set for Bradford and it may be beneficial to engage with the District in question to develop links and shared learning.

Table 2   Employment of People with Learning Disabilities in Bradford, 2015/16

		Bradford		Yorkshire and Humber	England		
!ndicator	**Period**	**Count**	**Value**	**Value**	**Value**	**Lowest**	**Highest**
Proportion of supported working age adults with learning disability in paid employment (%)	2015/16	80	5.40%	6.30%	5.80%	0.00%	22.00%

Source: Public Health England

Employment in People with Autism

A 2016 report published by the UK National Autistic Society found that:
- Just **16%** of autistic adults are in full-time paid work (static since 2007)
- Overall, only 32% of autistic adults are in some kind of paid work
- **77%** of unemployed autistic adults *want to work*.
- 60% of employers would worry about getting support for an autistic employee wrong
- 60% also said they did not know where to go for support or advice about employing an autistic person

The report expressed the fear that without a better understanding of autism from both employers and the Government, autistic adults will continue to be left behind, their abilities overlooked [6].

Employment of People with Autism in Bradford

Table 3 below shows the employment status of people with Autism in Bradford as at January 2019. As can be seen, the number actively seeking work is extremely small, however there are a significant number of cases where employment status is not recorded which may skew conclusions drawn from this.

Table 3   Employment Status of People with Autism, Bradford January 2019

Employment Status	Type	
	Aspergers/High Functioning	Autism excluding Aspergers
Seeking work	<5	<5
Not seeking work	31	119
Not Recorded	39	36

High Cost Placements

There are strong interdependent links between degree of intellectual disability, behaviour, service use and costs, with higher costs being associated with more severe intellectual disabilities and more challenging behaviour [5]. As such, a number of our people with LD or Autism are cared for in high cost units where numbers of staff for each person are higher, and specialised support is offered often on a 24 hr basis

An English study published in 2015 investigated the characteristics of the highest cost residential placements provided for adults with learning disabilities in the South East of England, comparing findings with a previous survey [6]. Information was gathered concerning 105 individuals of whom 70% were male and who had a mean age of 32 years. Their needs were reported to include: autism (71%) challenging behaviour (88%) offending behaviour (24%) mental health diagnosis (18%). There care was provided in :

- Residential care (55%)
- Supported living (17%),
- Hospital (15%),
- Secure/ medium secure units (11%)
- Forensic settings (10%).

The average placement cost was **£200,000 per annum** with a range from £81,000 to £430,000 per annum.

Economic Costs of Learning Disabilities and Autism in Bradford

A 2009 UK study where data on prevalence, level of intellectual disability and place of residence were combined with average annual costs of services and support, together with the opportunity costs of lost productivity (i.e. indirect costs), found that [x]:

- The costs of supporting *children* with Autism were estimated to be **£2.7 billion each year** in the UK.
- *For adults*, these costs amounted to **£25 billion each year**.
- The **lifetime cost**, after discounting, for someone with Autism **with** LD was estimated at approximately **£1.23 million**, and for someone with Autism **without** intellectual disability was approximately **£0.80 million**.

Autism

Given the research cited above in addition to the time lapsed since it were published, it is reasonable to estimate that the total economic costs of Autism, both direct and indirect, to Bradford are, per annum, at least:

- For children only: £27 million
- For children and adults: £270 million

What Does This Mean for People with LD/Autism in Bradford?

Evidence clearly shows that people with LD and Autism can make a valuable economic contribution to Bradford by finding and maintaining suitable and sustainable employment. The benefits to both businesses and people with LD/Autism have been clearly demonstrated in multiple studies and make a compelling case for broad strategic support to find work for these people. Nonetheless, the data presented here clearly show that we are falling far short of achieving any significant indication that we are providing/achieving these employment opportunities in Bradford.

Evidence suggests that changes to the employment situation for workers with LD/Autism will require major shifts policy, workplace practices and vocational preparation of youth with LD/Autism [4]. In addition, a number of dedicated approaches have been developed such as personalised supported employment models (British Association of Supported Employment [7]) and Job Coaching (Department of Health and Valuing People Now, 2011). Also key to supported employment's success is having an emphasis on employers as an equal consumer of its services alongside the people with a learning disability they employ [2].

With effective support, people with LD/Autism can access the proven benefits of long-term work. This will require political/strategic support, and also more co-operation between employment services, social workers and health professionals, from psychiatrists and mental health nurses to psychotherapists and occupational therapists.

Strategic Recommendation

1. **A communications exercise should be undertaken to publicise the benefits for businesses that employ people with a learning disability**
2. **A dedicated programme should be established to address the small numbers of people with LD and Autism who are seeking work**
3. **The British Association of Supported Employment should be approached as a partner in developing access employment for people with LD and Autism**

REFERENCES

1. Modini, M. et al., 2016. The mental health benefits of employment: Results of a systematic meta-review. Australasian psychiatry : bulletin of Royal Australian and New Zealand College of Psychiatrists, 24(4), pp.331–336.
2. Mencap, A systematic review of the literature on the benefits for employers of employing people with learning disabilities, 2017, pp 25-29

3. Beyer, S. and Robinson, C. (2009). A Review of the Research Literature on Supported Employment: A Report for the Cross-Government Learning Disability Employment Strategy Team. London: Department of Health.

4. Lysaght, R., Ouellette-Kuntz, H. and Lin, C.J. (2012). Untapped potential: Perspectives on the employment of people with intellectual disability. Work, 41, 409-422.

5. Knapp, M.; Comas-Herrera, A.; Astin, J.; Beecham, J; Pendaries, C. (2005). Intellectual disability, challenging behaviour and cost in care accommodation: what are the links? London: LSE Research Articles Online.

6. Deveau, R. et al., Characteristics of the most expensive residential placements for adults with learning disabilities in South East England: a follow-up survey. emeraldinsight.com

7. British Association of Supported Employment (2017). What is Supported Employment? Available at: http://base-uk.org/what-supported-employment (Accessed 20/12/2018)

Section 10 - Accommodation

Having a place to live is a key requirement for people to achieve independent living [1].

- Many people with learning disabilities want to share but with only a few others and with people that they already know
- Some want to live in ordinary housing by themselves
- Some will choose to live in their own homes but like them to be grouped with others

People with learning disabilities can live successfully in different types of housing, from individual self-contained properties, housing networks, group homes, and shared accommodation schemes, through to village and other forms of intentional community. They can cope with the full range of tenures, including home ownership, and can be effectively supported to live as independently as possible in ordinary housing in the community, without creating institutional models of housing and care [2].

Some people, for example some autistic people, may not need significant physical adaptations, but the location and design of their home may still be important, particularly if they have sensory needs [3]. They may need to live away from busy, noisy roads or bright lights. There may be specific triggers of certain types of behaviour which exist within the house or in the surrounding area [4].

> **Everyone should either be offered their own tenancy in settled accommodation or own their own home. This can be in small-scale supported living schemes or other bespoke housing options [5]**

Where do People with Learning Disabilities Live?

Many people with LD live with their family, some rent and a small proportion of people own their own home. Others live in some form of supported accommodation. Over half of people with a learning disability (55%) live with their parent/s, which varies by severity. For example, the majority of people with severe and profound multiple learning disabilities live with a parent [6] and are less likely to be in employment, education and/or training, and experience problems with social deprivation [6].

In England, the proportion of adults aged 18-64 with a LD who live in their own home or with their family increased from **70%** in 2011-12 to **76.2%** in 2016-17. In 2016-17 there were **99,193** adults receiving long-term disability support who were living in their own home or with their family in England (see Table 1 and Figure 1 below).
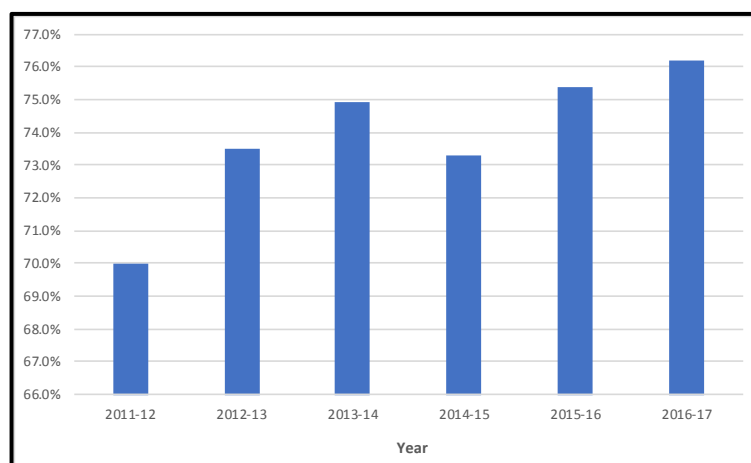
Table 1   Proportion of Adults with a Learning Disability who Live in their Own Home or with their Family, England 2011-17

Year	Proportion of Adults with a Learning Disability who live in their own home or with their Family
2011-12	70.0%
2012-13	73.5%
2013-14	74.9%
2014-15	73.3%
2015-16	75.4%
2016-17	76.2%

Source: NHS Digital

Although placing people with LD in clusters of housing is generally less expensive to deliver, dispersed housing is a superior solution when considering cost combined with **quality of life outcomes** (with the exception of village communities for people with less severe learning disabilities) [7].

Figure 1   Proportion of Adults with a Learning Disability who Live in their Own Home or with their Family, England 2011-17

Source: NHS Digital

Table 2 and Figure 2 below illustrates the predicted rise to 2030 in the numbers of people with LD in England who live with a parent. Although some of the trends are subtle, it can be seen that:

- There is a steady upward trend in the total number

- The 18-24 group displays an initial plateau in 2020 transitioning to a higher plateau in 2035.
- The reciprocal of this is observed in the 25-34 group
- The 45-54 and 55-64 groups show slight upward and downward trends respectively

Table 2   People aged 18-64 predicted to have a moderate or severe learning disability
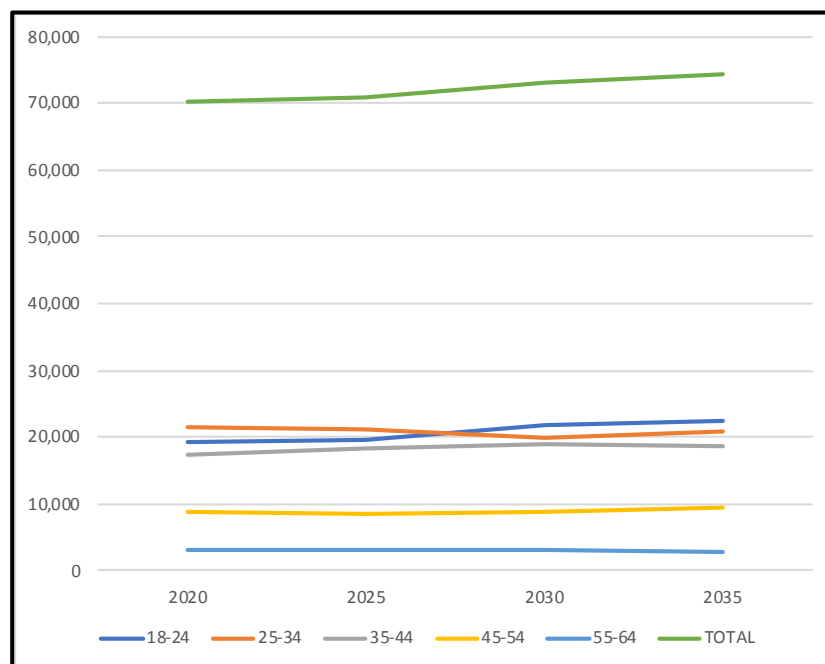
and be living with a parent, by age, England, projected to 2035

	2020	2025	2030	2035
People aged 18-24 predicted to be living with a parent	19,327	19,593	21,876	22,285
People aged 25-34 predicted to be living with a parent	21,410	21,054	20,050	20,780
People aged 35-44 predicted to to be living with a parent	17,437	18,446	19,042	18,795
People aged 45-54 predicted to be living with a parent	8,948	8,522	8,865	9,396
People aged 55-64 predicted to be living with a parent	3,160	3,293	3,134	2,974
Total population aged 18-64 predicted to be living with a parent	70,282	70,908	72,967	74,230

Source: PANSI

Figure 2   People aged 18-64 predicted to have a moderate or severe learning disability

and be living with a parent, by age, England, projected to 2035

National Strategic Approach

NHS England, the Local Government Association and the Association of Directors of Adult Social Care set out a commitment to significantly increase housing options for people with learning disabilities in the **Building the Right Home [5]** document. By enabling people to access the right home and support at the right time the intention is that this will also support the reduction in overall **inpatient** capacity by **March 2019**.

Independent Living

The Care Act stipulates that Local Authorities must provide or arrange services that **help prevent people developing needs for care and support** or **delay people deteriorating such that they would need ongoing care and support** [8]. An example indicator of independent living is the provision of support packages. In England, during 2016/17 **28.6%** of Learning Disability Needs Assessment supported adults (aged 18-64 years) received a direct payment with this figure showing year on year increases.

Supported Accommodation

Supported housing provides disabled people with

- Their own front door
- Independent living in their own home
- On-site care and support available 24 hours a day, 7 days a week.

Supported housing varies, - people may have their own flat, house or bungalow within a wider development for other supported people - sometimes with additional communal space. Supported housing also lends itself to mixed tenures so that people can have the option to rent, part buy or buy outright. A scheme can also operate for a mixed group of people with varying levels of needs. Supported housing can also be an environment where a blend of services can **safely manage clinical risks of more high-risk inpatient populations [5]**.

Housing Related Support

Housing related support services help people to live independently or move on to independent living, this can include people receiving support to:

- Set up and maintain their home
- Manage safety and security of their accommodation
- Maintain their health and wellbeing
- Develop their life skills, such as cooking, cleaning and budgeting skills
- Apply for benefits
- Access other services
- Get advice and advocacy in connection with housing or tenancy matters

Inpatient Services [9]

For a minority of children, young people and adults with LD and/or autism who display behaviour that challenges, including those with a mental health condition, we remain too reliant on inpatient care. Some of these people will have been in hospital for many years.

The national strategic stance aims has been to move money into community services in order to **reduce their usage of inpatient provision by approximately 50% over the three years to 2019.** These plans aim to result in the development of a range of new community services and the closure of hospital units. A maximum capacity of 10-15 inpatients per million population in CCG commissioned beds (such as assessment and treatment units) is envisaged, along with, a maximum of 20-25 inpatients per million population in NHS England-commissioned beds (such as low-, medium- or high-secure services).

Accommodation in Bradford

Note – a comprehensive housing mapping exercise is currently being undertaken at CBMDC, with LD housing included as part of the larger exercise. This piece of work will inform planning policy and the housing needs of the district for the future, determining the type of housing being built and the locations among other key aspects This Health Needs Assessment will not encroach on or try to predict the outcomes of this exercise but instead will present results from a current Adult Social Care summary, and a sample of 190 patients at Waddiloves Health Centre in advance of the publication of the mapping exercise.

Current Housing

In the interim, within LD housing we currently have existing stock which largely consists of **general let shared homes**. There have historically been issues with managing voids in these properties given compatibility between individuals with LD/Autism can be difficult to navigate.

In addition, there is a concerted effort through the Transforming Care Programme to provide a range of housing needs to accommodate the planned reduction in inpatient facilities/admissions. In response to the above context CBMDC is delivering up to 100 bed spaces over the next year of **high specification bespoke LD housing** in Bradford and Keighley. It is also essential that we map the housing needs of Bradford's LD/Autism population over the next 5-10 years in order to accommodate the diversity of need and it is further essential to ensure housing plays a central part of support planning for adults and young people leaving institutional care.

Strategic Direction

CBMDC is moving away from the use of residential properties and prioritising specialist housing needs for people with complex care needs requiring discharge from ATU and residential settings. These individuals may require adaptations that are not available within general housing such as; assistive technology (fob entry on doorways, motion sensors), sensory spaces and specialist materials for the

environment. The planned specialist housing will provide such high specification housing affording longevity and stability, however the properties are not aesthetically presented as a specialist home and are located in residential areas within local communities as opposed to annexed to medical institutions and so offer a real opportunity for inclusion.

Table 3 below shows the breakdown of housing type for the current Adult Social Care case load of people with LD. Clearly the largest group is those who are living in **settled mainstream housing** which is encouraging. People in supported accommodation make up the next highest group, followed by those living in registered care homes. The number where housing status is not recorded is relatively high.

Table 3   Adult Social Care Team Learning Disability Housing Caseload, January 2019

Accommodation Type	Number
Adult Placement Scheme	22
House rented from Council	6
House rented from housing	99
House rented from private	31
Lives in registered care home	150
Lives in own home	16
Not recorded	151
Settled Mainstream Housing	669
Sheltered Housing	10
Staying with friends	12
Supported Accommodation	341
Supported Group Home	12
Others	6
TOTAL	**1525**

Waddiloves Sample

The housing status is presented here for of a group of people attending with LD and Autism who were attending the Waddiloves Health Centre (see Section 5 – Secondary Care) in November 2018.

It should be noted that there is likely to be some bias to these results given that this is a selected group of people with LD and Autism who are presenting in need of the services at Waddiloves which may translate into need for a higher level of housing

support. Clearly though this will also give us a valuable idea of the level of need in this group of people
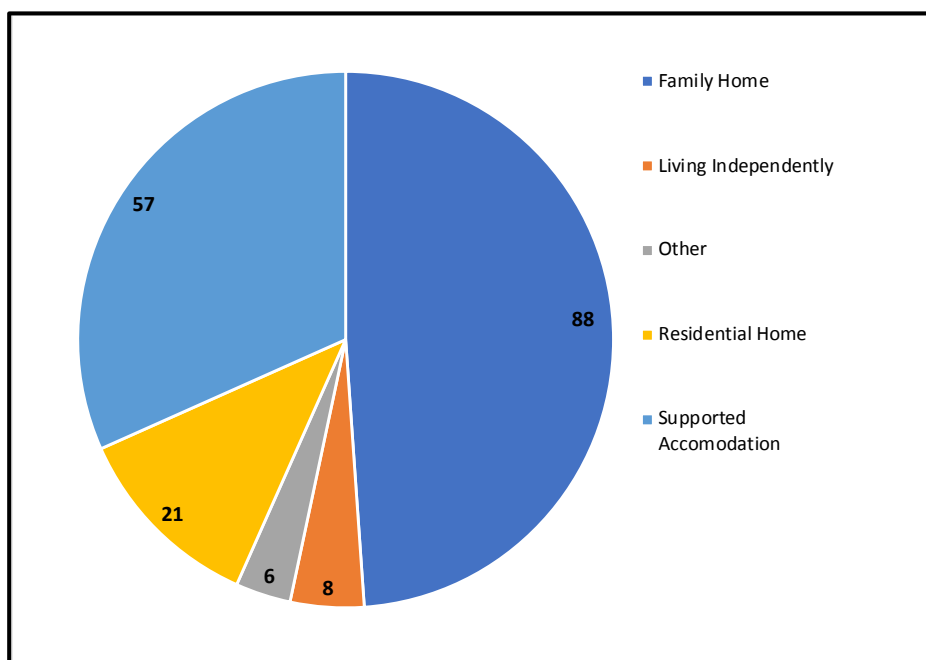
Table 4   **Accommodation Type, Waddiloves Sample, November 2018**

Accommodation Type	Number
Family Home	91
Living Independently	8
Nursing Home	7
Other	6
Residential Home	21
Supported Accomodation	57
Grand Total	**190**

As can be seen, the largest group is those living in the family home, which reflects the findings of the Adult Social Care sample shown in Table 3. Likewise, the second largest group is those living in supported accommodation.

Figure 3 below shows these results schematically (note a small number are not represented here due to masking of small numbers).

Table 4   **Accommodation Type, Waddiloves Sample, November 2018**

Finally, Table 5 below shows the sample based on Locality of origin (again a small number are not represented due to masking of small numbers). As can be seen, Keighley and District Localities source the majority of people.

Table 5   **Locality of Origin, Waddiloves Sample, November 2018**

Locality	Number	%
City	50	27.5%
District	69	37.9%
Keighley	82	45.1%
TOTAL	182	100.0%

What Does This Mean for People with Learning Disabilities and Autism in Bradford?

Accommodation is perhaps the most important aspect of the lives of our people with LD and Autism, particularly for those with mental health problems or sensory needs. It is encouraging that such a significant proportion of people with LD and Autism in Bradford are settled in mainstream accommodation, although it is important to recognise that those living with family may be relying on elderly parents for care. The findings of the housing mapping exercise will be crucial to establishing a baseline and a strategic direction going forward. These should be combined with the findings of this section and also Section 2 – Epidemiology to develop an accurate picture of developing need over coming years.

Strategic Recommendations

1. **The findings of the housing mapping exercise should be used to establish a baseline and strategic direction going forward.**
2. **These findings should be combined with the findings of this section and also Section 2 – Epidemiology to develop an accurate picture of developing need over coming years.**

REFERENCES:

1. Changing lives through real partnership: A new service model for people with learning disabilities
https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=2ahUKEwi52-3HrJrgAhXTSBUIHbfrDLcQFjAAegQIARAC&url=https%3A%2F%2Fwww.bradforddistrictsccg.nhs.uk%2Fseecmsfile%2F%3Fid%3D1017&usg=AOvVaw125HGNlkzHo93iz4W7d923 (accessed 28/01/19)

2. Laing and Buisson, Illustrative Cost Models in Learning Disabilities Social Care Provision. Department of Health. May 2011.
3. Department of Health (2014) 'Think autism: fulfilling and rewarding lives, the strategy for adults with autism in England: an update', London: Department of Health.
4. A Practical Guide for Registered Social Landlords: Housing and Autism Spectrum Disorder, Glasgow City Council, 2010:
5. Building The Right Home. Local Government Association, ADASS, NHS England. 2018.
6. Emerson E, Hatton C. CEDR Research Report 2008 (1): People with Learning Disabilities in England.
7. Mansell, J. & Beadle-Brown, J., 2009. Dispersed or clustered housing for adults with intellectual disability: A systematic review. Journal of intellectual & developmental disability, 34(4), pp.313–323.
8. Legislation.gov.uk. (2014). Care Act 2014. [online] Available at: http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted (Accessed 28/01/19]
9. Building the Right Support. Local Government Association, ADASS, NHS England. 2015.

Section 11 – Comorbidities

Comorbidities in LD

People with LD are known to have greater healthcare needs with high levels of premature mortality, with the 2013 confidential inquiry into premature deaths of people with LD in England reporting a greater burden of potentially avoidable deaths that can be prevented with good-quality health care [1]. Additionally, as people get older, their probability of being diagnosed with multiple diseases ('multimorbidity') rises considerably, with a recent large UK study finding that the prevalence of people with more than one disease increases substantially with age and is present in most people aged 65 years and over [2]. With the general population, both with and without LD, living longer, we can expect to see more older people with LD and thence with more comorbidity to diagnose and manage.

In 2016, a study undertaken in 400 General Practices in England used the data from a large primary care database to describe chronic disease, comorbidity, disability, and general practice use for adults with LD, and compared these to the general population [3]. The study showed that people with LD have generally higher overall levels of chronic disease with greater overall primary care use, and that this need is greatest in people living in communal settings. However, patients with LD were *less* likely to have longer doctor consultations and had lower continuity of care with the same doctor. 1 in 10 of the people in this study had an additional diagnosis of autistic spectrum disorder. Additionally, a 2015 study of nearly 1.5 million primary care patients undertaken in Scotland [4] found that people with LD were significantly more likely to have more health conditions with **14 physical conditions** significantly more prevalent, and **5 of 6 mental health conditions** significantly more prevalent. For the adults with intellectual disabilities, no gradient was seen in extent of multimorbidity with increasing neighbourhood deprivation, with findings similar in the most affluent and most deprived areas. Other and more recent studies have corroborated these findings, showing that British adults with LD have markedly poorer health than their non-disabled peers on the majority of indicators investigated including self-rated health, multiple morbidity, arthritis, cancer, diabetes, obesity, lung function, visual impairment and polypharmacy [5, 6].

But what about the health of the 'hidden majority' of adults with primarily mild intellectual disability who do not use intellectual disability services?

A 2016 UK study of more than 20,000 people identified 300 with LD and reported that the 'hidden majority' of adults with primarily mild intellectual disability who do not use intellectual disability services have significantly poorer health than their non-disabled peers [5]. This included self-rated health, multiple morbidity, arthritis, cancer, diabetes, obesity, measured grip strength, measured lung function and polypharmacy. The authors concluded that this observation may, in part, reflect
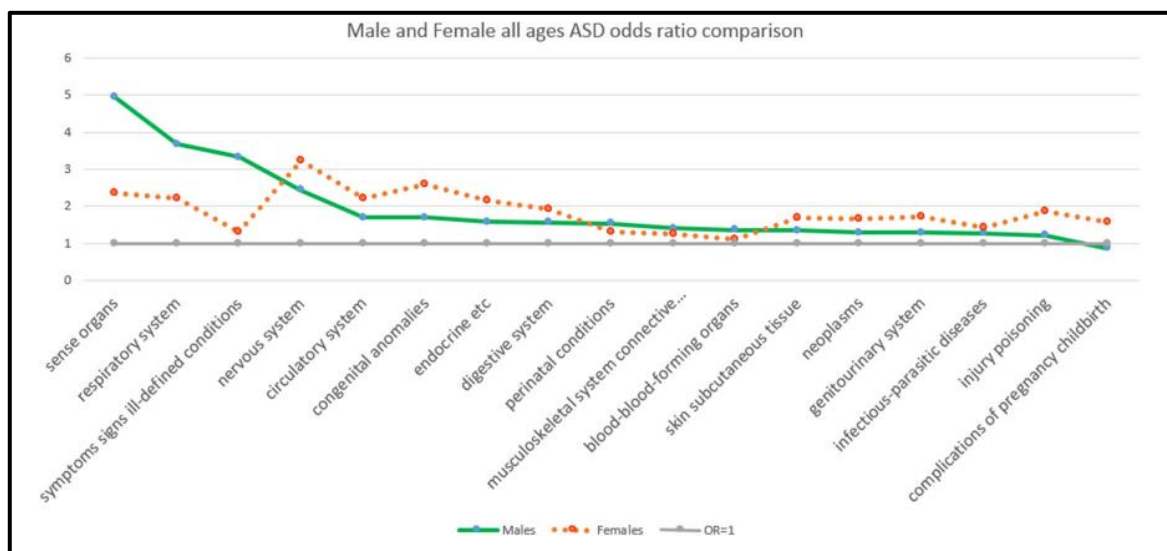
increased risk of exposure to well established 'social determinants' of poorer health in this group of people.

Comorbidities in Autism

Evidence on the extent of comorbidity in people with LD is generally lacking, however a Canadian study published in 2018 analysing relationships between autism and comorbid diagnoses (defined by ICD-10 class) found a pattern of increased odds of diagnoses with these comorbidities across the ages 3 to 18 [7], thus suggesting that Autism is associated with a range of comorbidities.

Additionally, in respect of Autism, it is important to recognise that X% of people with LD are also autistic and hence there will be considerable crossover into the LD comorbid population. Figure 1 below shows this pattern.

Figure 1 Odds ratios comparison of the presence and absence of ASD by major class ICD 9
diagnosis ranked by sex from highest to lowest by males.

Two of the areas of particular impact and concern in LD and Autism are **Mental Health** and **Obesity**.

Mental Health

Population-based estimates suggest in the UK that **40%** (28% if problem behaviours are excluded) of adults with LD experience mental health problems **at any point in time**. An estimated **36%** (24% if problem behaviours are excluded) of children and young people with learning disabilities experience mental health problems at any point in time. These rates are much higher than for people who do not have learning disabilities [8]. NICE Guideline 54, *Mental health problems in people with learning disabilities: prevention, assessment and management* covers preventing, assessing

and managing mental health problems in people with learning disabilities in all settings (including health, social care, education, and forensic and criminal justice). It aims to improve assessment and support for mental health conditions, and help people with LD and their families and carers to be involved in their care.

The incidence of mental illness in autism is higher than in intellectual disability alone and underdiagnosis of mental illness is a risk [9]. Recent studies have shown that approximately **70%** of people with autism also meet diagnostic criteria for at least one other (often unrecognised) psychiatric disorder that is further impairing their psychosocial functioning [10], and that between **69–79%** of individuals with Autism experience at least one additional psychiatric condition **during their lifetime** compared to rates of lifetime psychiatric disorder of approximately **40%** in the general population [11].

Obesity

It's been recognised for many years that people with LD are at increased risk of being overweight or obese compared to the general population, with poorly balanced diets and very low levels of physical activity. This risk, in turn, increases the likelihood of a range of health and social problems [12]. The most recent data on the prevalence of excess weight in people aged 18 and older with LD is based on analysis of data from GPs across the whole of England. This showed that, in comparison to the general population, a smaller proportion of people with LD are in the milder category termed **overweight** (BMI 25-30) (30% of men and 25% of women compared to 41% of men and 31% of women without a learning disability). However, there are higher proportions in the more severe category of **obese** (BMI 30+) (**31%** of men and **45%** of women compared to **24%** of men and **27%** of women without a LD) [13].

NICE QS111 *Obesity in adults: prevention and lifestyle weight management programmes* states that treatment, care and support for obesity and the information given about it, should be accessible to people with additional needs such as physical, sensory or learning disabilities [14]. Additionally, PH42 *Obesity in adults: prevention and lifestyle weight management programmes* states that community lifestyle services focusing on prevention of obesity specifically identifies those who are less likely to access services, people a learning or physical disability as being particularly able to benefit from these services [15].

A 2016 UK systematic review of the evidence on obesity and overweight prevalence in the population of children with Autism found that eight of eleven studies included reported higher obesity rates among children with Autism compared to those without. The highest rate was 30% [16]. A further worldwide systematic review found that the prevalence of **obesity** (i.e. BMI 30+) was significantly higher in individuals with Autism than in controls. However, the prevalence of **overweight** (i.e. BMI 25-30) in individuals with ASD was **not** significantly different from that in controls [17]. Interestingly, a 2017 study found a decline in prevalence of obesity with advancing age among children without Autism [18].

Given the issues and evidence outlined above, it is clear that we should give consideration to the needs of people with LD and Autism and their carers in the context of all of their medical and social needs, not just those relating specifically to their LD or Autism. In order to understand this, we present below a further analysis of those patients with a diagnosis of LD and Autism who also have an additional diagnosis of a long-term condition as recorded on the primary care disease registers.

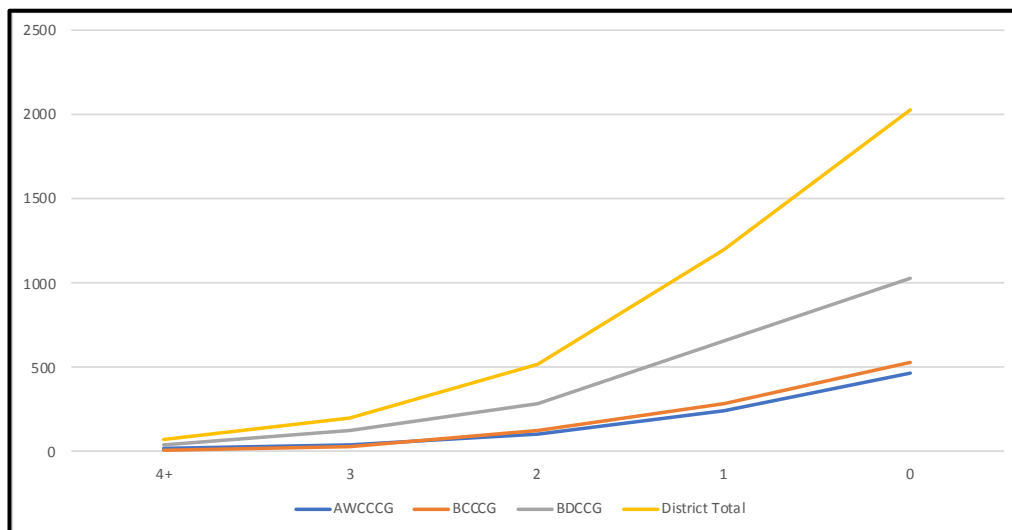# Multimorbidities in People with LD and Autism in Bradford

Table 1 and Figure 2 below show the overall numbers of Long Term Comorbidities in people with LD in Bradford, by CCG. Crude rates per 100,000 population are also shown.

Table 1   Multimorbidity in People with Learning Disability in Bradford, by CCG 2018

Number of Comorbidities	AWCCCG	BCCCG	BDCCG	District Total
4+	22	14	39	75
3	46	28	129	203
2	108	129	285	522
1	246	290	663	1199
0	464	534	1031	2029
TOTAL	886	995	2147	4028
Rate/100,000 pop.	557.01	709.08	644.80	636.98

Source: eMBED

Figure 2   Multimorbidity in People with Learning Disability in Bradford, by CCG 2018

Source: eMBED

Key Observations - LD:
- There is a negative correlation between number of LTCs and number of patients
- The number of people with 4+ LTCs is small compared to other numbers in all CCGs
- There is a sharp jump in numbers from 2 to 0 in BDCCG and the District overall
- The patterns in AWCCCG and BCCCG follow each other closely

- The rate of LTCs per 100,000 pop. is notably higher in BCCCG and lower in BDCCG
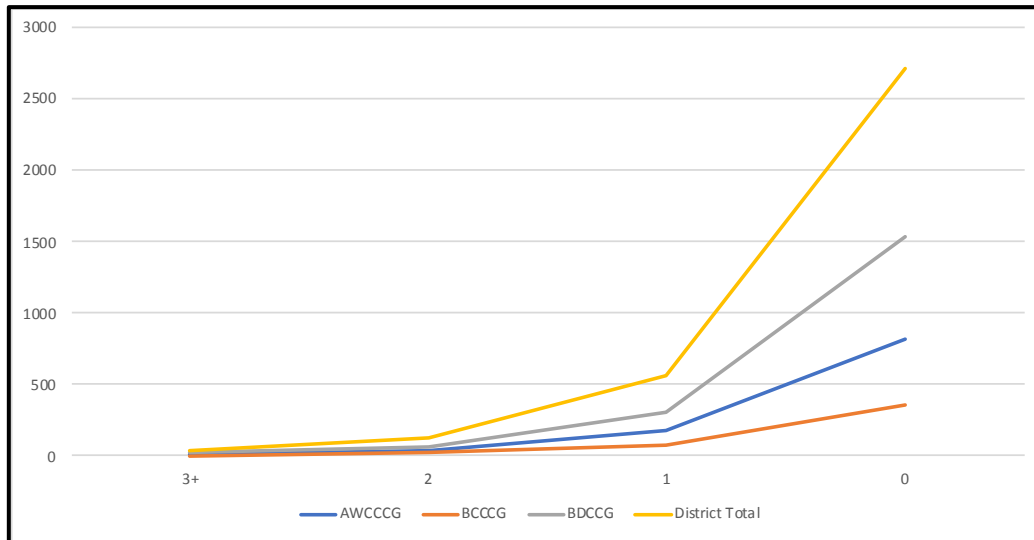
Table 2 and Figure 3 below show the overall numbers of Long Term Comorbidities in people with Autism in Bradford, by CCG. Crude rates per 100,000 population are also shown.

Table 2   **Multimorbidity in People with Autism in Bradford, by CCG 2018**

Number of Comorbidities	AWCCCG	BCCCG	BDCCG	District Total
3+	9	4	23	36
2	38	20	66	124
1	173	82	310	565
0	819	357	1540	2716
TOTAL	1039	463	1939	3441

Rate/100,000 pop.	653.20	329.96	582.33	544.15

Source: eMBED

Figure 3   **Multimorbidity in People with Autism in Bradford, by CCG 2018**

Source: eMBED

Key Observations - Autism:
- There is a negative correlation between number of LTCs and number of patients
- The number of people with 3+ LTCs is very small compared to other numbers in all CCGs
- There is a sharp jump in numbers from 2 to 0 in all CCGs and the District overall
- The overall pattern and shape of rising numbers of people as numbers of LTCs fall is followed by all three CCGs with a sharper rise from 1 to 0 in BDCCG
- The rate of LTCs per 100,000 pop. is notably higher in BCCCG and lower in BDCCG

The remainder of this section of the report relates to LD only, as the 2017 analysis that informs the data referred to did not include people with Autism.
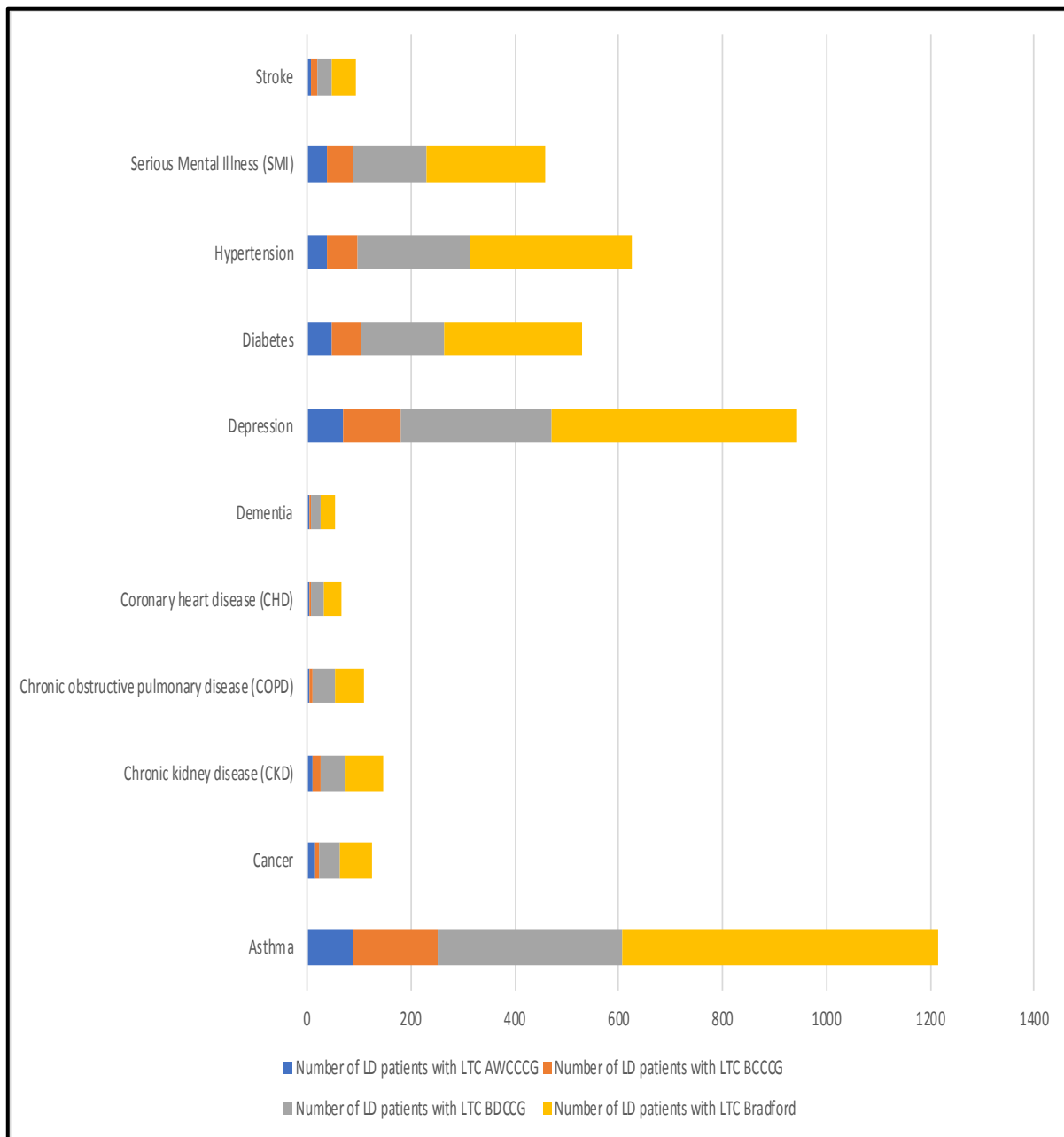
Table 3 and Figure 4 below show the actual conditions that constitute the comorbidities of people with LD in Bradford, by CCG

Table 3 Comorbid Long Term Conditions in People with LD, by Condition, Bradford by CCG, 2017

LTC	Number of LD patients with LTC			
	AWCCCG	BCCCG	BDCCG	Bradford
Asthma	89	164	354	607
Cancer	14	9	39	62
Chronic kidney disease (CKD)	10	17	46	73
Chronic obstructive pulmonary disease (COPD)	6	6	42	54
Coronary heart disease (CHD)	5	4	24	33
Dementia	3	5	19	27
Depression	69	113	290	472
Diabetes	48	54	163	265
Hypertension	40	56	217	313
Serious Mental Illness (SMI)	38	51	141	230
Stroke	8	11	28	47

Source: Dr Foster 2017

Figure 4 Comorbid Long Term Conditions in People with LD, by Condition, Bradford by CCG, 2017

Source: Dr Foster 2017

Key Observations:

- **Asthma** constitutes the most prevalent LTC in all three CCGs
- **Depression** constitutes the second most prevalent LTC in all three CCGs
- **230** people with LD have a Serious Mental Illness
- Hypertension and Diabetes show worryingly high numbers in all three CCGs, both of these conditions being related to obesity, smoking and lack of physical exercise
- Numbers of people with both LD and Dementia seem small and may be due to underdiagnosis

What does this mean for people with Learning Disabilities and Autism in Bradford?

What is clear from this section is that people with LD and Autism are more likely to suffer from a wide range of illnesses than their counterparts without LD and Autism. What is *important* is that many of these are preventable, easily diagnosed and eminently manageable. People with LD and Autism must be able to access care for *primary prevention* (lifestyle advice and support to prevent illness happening), and also *secondary prevention* (early diagnosis and timely and effective management of any illnesses that should arise). Health and social care workers should be vigilant and given the time, training and resources to make diagnoses and provide evidence-based care – NICE guidelines should be referenced, and clinical networks established to enable access to expert opinion when required. Under diagnosis is not acceptable, and creates a pernicious health inequality, statutory organisations have a duty to ensure that this is minimised. Carers know their friends and loved ones best and must be supported to bring concerns to professionals who will give these the credence they deserve.

Strategic Recommendations

1. **The Transforming Care Partnership Board should lead work to highlight the findings of this section to primary care commissioners and providers and also to secondary care clinicians**
2. **Further analysis of comorbidities across CCGs should be undertaken, incorporating factors such as deprivation and ethnicity**
3. **The Adult Social Services Department at Bradford Metropolitan Council should work in partnership with healthcare services and academics as health status is also closely allied to social circumstances**
4. **A Network approach should be developed to implement relevant NICE guidance in health and social care services**

REFERENCES

1. Heslop, P. et al., 2014. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. The Lancet, 383(9920), pp.889–895.
2. Barnett K, Mercer SW, Norbury M, Watt G, WYKE S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. Lancet. 2012 Jul 7;380(9836):37–43.

3. Carey, I.M. et al., 2016. Health characteristics and consultation patterns of people with intellectual disability: a cross-sectional database study in English general practice. *The British journal of general practice: the journal of the Royal College of General Practitioners*, 66(645), pp.e264–70.

4. Cooper, S.-A. et al., 2015. Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis. BMC family practice, 16, p.110.

5. Emerson, E. et al., 2016. The physical health of British adults with intellectual disability: cross sectional study. *International Journal for Equity in Health*, 15, p.11.

6. Kinnear, D. et al., 2018. Prevalence of physical conditions and multimorbidity in a cohort of adults with intellectual disabilities with and without Down syndrome: cross-sectional study. BMJ Open, 8(2), p.e018292.

7. Cawthorpe D, A 16-year cohort analysis of autism spectrum disorder-associated morbidity in a pediatric population.

8. NICE Guideline 54, *Mental health problems in people with learning disabilities: prevention, assessment and management.* National Institute for Health and Clinical Excellence 2016.

9. Brereton, A.V., Tonge, B.J. & Einfeld, S.L., 2006. Psychopathology in children and adolescents with autism compared to young people with intellectual disability. Journal of Autism and Developmental Disorders, 36(7), pp.863–870.

10. NICE CG128. Autism spectrum disorder in under 19s: recognition, referral and diagnosis. National Institute for Health and Clinical Excellence 2017.

11. Howes, O.D. et al., 2018. Autism spectrum disorder: Consensus guidelines on assessment, treatment and research from the British Association for Psychopharmacology. Journal of psychopharmacology (Oxford, England), 32(1), pp.3–29.

12. Obesity and weight management for people with learning disabilities: guidance. Public Health England, 2016.

13. Health and Care of People with Learning Disabilities: Experimental Statistics: 2014 to 2015. Office for National Statistics 2016.

14. QS111 Obesity in adults: prevention and lifestyle weight management programmes. National Institute for Health and Clinical Excellence 2016.

15. PH42 Obesity: working with local communities. National Institute for Health and Clinical Excellence 2017

16. Psychiatry, F.B.J.2016, Prevalence and correlates of obesity in childhood autism spectrum disorders: A literature review. researchgate.net

17. Zheng, Z. et al., 2017. Association among obesity, overweight and autism spectrum disorder: a systematic review and meta-analysis. Scientific reports, 7(1), p.11697.

18. Must, A. et al., 2017. The Effect of Age on the Prevalence of Obesity among US Youth with Autism Spectrum Disorder. *Childhood obesity (Print)*, 13(1), pp.25–35.

Section 12 – Dietetics and Dental Health

Dietetics is included in this report as a discrete section due to the importance of this specialty in managing swallowing – dysphagia and aspiration pneumonia are key causes of death in people with learning disabilities. Additionally, obesity is a key comorbidity in people with learning disabilities (see Section 11 – Comorbidities)

Obesity and Overweight

The prevalence of obesity in adults with intellectual disabilities has consistently been reported to be higher than the general population [1, 2, 3]. Obesity affects **46%** of female and **32%** of male adult patients with intellectual disabilities who are registered with primary healthcare in England and who have had a BMI check, compared to **30%** of female and male adult patients without intellectual disabilities [4].

Adults with intellectual disabilities who are obese are more at risk of experiencing serious obesity-related conditions such as coronary heart disease, stroke and type 2 diabetes than adults without intellectual disabilities [3]. This represents a significant health inequality.

Reasons for the high prevalence of obesity among this population are complex [5]. Contributing factors may include poverty, poor nutrition, genetics, medication, poor dietary habits, very high levels of physical inactivity and overfeeding by carers or support workers to prevent boredom or conflict [3, 6]. Adults with intellectual disabilities may be unable to access activities and services to help them eat well, live well and manage their weight because of limited support, restrictions to personal income, inaccessible services or activities, as well as carers' issues and concerns [5].

Eating and Drinking Difficulties (Dysphagia)

Many paediatric health care professionals, in particular speech and language therapists (SLTs), focus on managing the needs of infants and children who have eating and drinking difficulties (dysphagia) in acute and community settings, with a typical caseload including a high proportion of children with LD and/or Autism [7]. Alongside eating and drinking difficulties, these children are likely to have significant cognitive needs as well as receptive and expressive communication difficulties. There are currently few reliable data on the prevalence of dysphagia in people with learning disabilities. Historically, estimates have ranged from **36%** (based on speech and language therapy caseloads) to over **70%** (however these figures are based on inpatient populations only). More recent studies have shown that about <u>**15%**</u> of adults with learning disabilities require support with eating and drinking and <u>**8%**</u> of those known to learning disability services will have dysphagia. This figure is likely to be an underestimate, as we know the signs of dysphagia (particularly when it is mild) can be missed. Therefore, not everybody with swallowing problems might be referred appropriately.

Services

In 2015, the US Academy of Nutrition and Dietetics issued a Position Statement stating that "Nutrition services provided by registered dietitian nutritionists (RDNs) and nutrition and dietetics technicians, registered (NDTRs), who work under RDN supervision, are essential components of comprehensive care for adults with intellectual and developmental disabilities (IDD) and children and youth with special health care needs (CYSHCN). Nutrition services should be provided throughout life in a manner that is interdisciplinary, family centred, community based, and culturally competent" [8].

Service Activity

Staff Numbers:
2 dietitians allocated to LD under the service agreement equating to **2 x 1.0WTE dietitians**.

Activity Levels:
Annual activity report for Q1-Q4 (April 2017 – Mar 2018):
- **123 new patient referrals for the year**,
  A review historic reports suggests that this is consistent with new patient activity
  levels over the past 4 years.
- **821 total face to face or telephone contacts**
  This includes new, follow-up and review contacts for the year.

Work Patterns:
A 4 week activity audit report carried out in 2017 mapped the specific activities undertaken by LD dietitians. The report showed the following
- The key area of work is patient focused activity taking up 65% of capacity
- 15% time is allocated to service development which is felt to be appropriate for a band 6 dietitian job plan, with this time used to deliver change, quality improvements and improve the operational structure of the service.
- The remaining 20% of time consists of a mixture of activities (training students, travel, CPD, mandatory training, non-patient related meetings, appraisals, 1-1 meetings)

Workload:
The audit used the British Dietetic Association (BDA) workload audit tool. The BDA splits patient focused activity into 5 sub sections, of which 4 are relevant to LD
1. Direct patient contact - inpatient (usually face to face and including all the associated activities such as note writing)
2. Direct patient contact – outpatient (usually face to face and including all the associated activities such as note writing) Includes phone consultations

3. MDT meetings and case conferences that do not involve direct communication with the patient or representative (Indirect Patient Activity)
4. All other indirect patient activities that do not involve direct communication with the patient e.g. telephone conversations with other HCPs, emails and all other patient related documentation
5. Travel to and from patients home or other off site location for patient care

The audit revealed that in LD the SLTs spend most of patient focused time on 4. All other indirect patient activities, with over 50% of the total patient contact falling here. This highlights the fact that the bulk of the work is done after the visit/appointment, i.e. a dietetic direct patient contact may take 45 – 60 minutes to complete but the post interview workload will take up significantly more time. This will include coordinating care, meeting/liaising with other healthcare practitioners and social services and calling day services and care homes. This is not reflected in the annual activity report as only face to face or pre-booked telephone review as a contact are measured due to limitations in the system at BTHFT.

Training
Rolling out currently is training sessions for the LD care homes/providers. These will be setting standards of practice for managing malnutrition & healthy eating in care settings then training providers and staff to meet the standards followed by auditing practice to ensure the training is having an impact. The training will link into CQC assessments and NICE guidelines.

Currently care providers are not monitored for quality outside CQC inspections and cannot access nutrition training courses. There may be quality gaps and inconsistent practice which need to be addressed.

There is a long list of providers wanting to access this training and it will improve the quality of care for people with LD in the community and mean that resources are used to have a wider impact.

Waiting Times
The Dietetics team has targeted faster access to the service as one of their 2016-2017 objectives, setting targets to see urgent new referrals within 2 weeks and non-urgent new referrals within 9 weeks (half the 18 week RTT). The Systmone waiting list is set up to enable/monitor this and urgents are often seen in less than 2 weeks, non-urgent in less than 4 weeks. Urgent referrals are always seen within 2 weeks and no one waits over 9 weeks unless there are circumstances out of their control (appointment cancellations, service users on holiday)

Effectiveness of Interventions

Reviews of weight management interventions for adults with intellectual disabilities who are obese have found a lack of evidence-based interventions for this population and a lack of controlled trials and qualitative research in this field [3, 5].

Key Issues

In a *mainstream* community dietetic service you would expect to see the bulk of patient focused activity coming from 2. Direct patient contact because you see the patient, complete your assessment/plan, document, set review, end the session until next time.

Dental Health

People with learning disabilities are reported to have a significantly increased incidence and severity of periodontal disease when compared to their non-disabled counterparts. The reasons for this are numerous and may include perpetuating medical conditions, personal and social circumstances, as well as poor dental access and education. Uncontrolled or advanced periodontal disease may not only cause tooth loss and its ensuing consequences but may also affect medical health, initiating or causing deterioration of systemic disease. Despite being a significant public health issue, very few data exist in current literature about the periodontal needs and treatment of patients with learning disabilities. This may largely be because research in this group is difficult and the spectrum of LDs is vast [9].

Prevalence

Unfortunately, there is a lack of consistency in reports on the prevalence of single physical health conditions in people with intellectual disabilities, due to the differences in methods used and populations studied. Reported prevalence rates for untreated dental caries range from 18% to 84% [10,11]. In addition, a 2017 analysis of multimorbidities in people with Down's Syndrome (DS) found that 15% of those with DS had dental/oral disease as against 12.2% in those without (whole cohort 12.7%) although confidence intervals were not calculated.

During 2009/10 and 2010/11 a survey of the dental health of adults with learning disabilities was undertaken by 27 primary care trusts (PCTs) across England [12]. The survey comprised a simple clinical examination and a questionnaire. Key results include:

- Among adults with LD, **63%** reported never or hardly ever feeling dental pain in the last 12 months and **9%** reported feeling dental pain fairly or very often. This compares to **70%** and **8%** in those without LD.
- In England, among adults with LD, **63%** reported that they brushed their teeth twice or more a day, **25%** said they brushed once a day, **3%** said they never cleaned their teeth. In those without LD, **75%** of adults without LD said that they cleaned their teeth at least twice a day, and **1%** said they never cleaned their teeth.

Local Activity

It is important to recognise that as well as providing standard dental care, dental services for people with LD services can involve significant challenges in respect of preparing the patient, reducing anxiety, and providing a calm, safe and reassuring environment.

Locally in Bradford there is a service to provide dentistry to people with LD, the key specialist element of this reflecting that these people would not be able to attend mainstream dentists due their behaviour, amount of desensitisation work they require, and large amounts of reasonable adjustments that would be required.

The Bradford District Care Trust Community Dental Service (CDS) provides Special Care Dentistry across Bradford and Airedale.

- CDSs are an NHS mandated service commissioned country wide not just locally.
- Special Care Dentistry is concerned with the improvement of the oral health of individuals with learning disabilities along with those who have physical, sensory, mental, medical, emotional or social impairment or disability or most frequently a combination of several of these.
- The CDS in Bradford provides dental care to patients with a LD from **8 health centres** and **2 local hospitals**
- In the month of January 2019 the service saw **>150 patients with a LD** across the service in a clinic setting and treated **6 patients in hospital**.
- There are **70 appointments per month** at Waddiloves which are usually filled.

Guidelines

In 2012 the British Society for Disability and Oral Health and the Faculty of Dental Health published Clinical Guidelines and Integrated Care Pathways for the Oral Health Care of People with Learning Disabilities [13]. Detailed exploration of these is beyond the scope of this report but they include:

- Barriers to Oral Health
- Improving Oral Health
- Education and Training
- Consent and Clinical Holding

What Does This Mean for People with Learning Disabilities and Autism in Bradford?

This report demonstrates how and why LD services operate differently from mainstream services and how this needs to be considered when evaluating activity levels of. This is particularly important for commissioners to understand.

What this means is that an LD dietetic service compared to a mainstream would look on the surface to be seeing less patients (less active) for the amount of dietitians or WTE but the LD service is spending much more time per patient on the indirect patient activities. Coming from a target driven service point of view this may seem

inefficient but indirect activity is a crucial part of the team's role and is part of the high quality service they provide.

> **Strategic Recommendations**
>
> **1. Dietetics should be recognised as a crucial and critical element of care in LD**
>
> **2. Commissioners should recognise that activity levels in dietetics and dentistry will be necessarily lower than mainstream services due to specialist elements of care involved**

REFERENCES

1. Harris, L. et al., 2015. A single-blind, pilot randomised trial of a weight management intervention for adults with intellectual disabilities and obesity: study protocol. *Pilot and feasibility studies*, 1(1), p.5.
2. Bhaumik, S. et al., 2008. Body mass index in adults with intellectual disability: distribution, associations and service implications: a population-based prevalence study. *Journal of intellectual disability research : JIDR*, 52(Pt 4), pp.287–298.
3. Spanos, D., Melville, C.A. & Hankey, C.R., 2013. Weight management interventions in adults with intellectual disabilities and obesity: a systematic review of the evidence. *Nutrition journal*, 12(1), p.132.
4. NHS Digital (2017) Health and care of people with learning disabilities. Available at: http://con tent.digital.nhs.uk/article/7543/Health-and-Care-of-People-with-Learning-Disabilities (accessed 07 November 2018).
5. Doherty, A.J. et al., 2018. Eating well, living well and weight management: A co-produced semi-qualitative study of barriers and facilitators experienced by adults with intellectual disabilities. *Journal of Intellectual Disabilities*, p.1744629518773938.
6. Emerson E. Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. Journal of Intellectual Disability Research 2003; 47(Pt 1):51-8.
7. Harding, C. & Cockerill, H., 2015. Managing eating and drinking difficulties (dysphagia) with children who have learning disabilities: What is effective? Clinical Child Psychology and Psychiatry, 20(3), pp.395–405.
8. Ptomey, L.T. & Wittenbrook, W., 2015. Position of the Academy of Nutrition and Dietetics: Nutrition Services for Individuals with Intellectual and Developmental Disabilities and Special Health Care Needs. *Journal of the Academy of Nutrition and Dietetics*, 115(4), pp.593–608.

9. Kaka, S. & Dickinson, C., 2017. Periodontal Treatment in Patients with Learning Disabilities Part 2: Professional Mechanical Intervention. Dental update, 44(3), pp.201–2– 205–6– 208.

10. Kendall, N.P., 1991. Oral health of a group of non-institutionalised mentally handicapped adults in the UK. Community dentistry and oral epidemiology, 19(6), pp.357–359.
11. Cumella, S. et al., 2000. Needs for oral care among people with intellectual disability not in contact with Community Dental Services. Journal of Intellectual Disability Research, 44(1), pp.45–52.
12. Dental Health among Adults with Learning Disabilities in England. Public Health England. Jan 2017
13. Clinical Guidelines and Integrated Care Pathways for the Oral Health Care of People with Learning Disabilities. British Society of Dental Health. 2012.

Section 13 – Education and Transition

The impacts of Learning Disabilities can be multiple and complex, and may affect such normal day-to-day activities as:

- **Cognition and communication** – the ability to perceive, think, concentrate, remember or learn the ability to communicate through oral or written language, perception of risk or danger
- **Manual dexterity and mobility** – the ability to co-ordinate movement to lift, carry or otherwise move or manipulate everyday objects and to move independently.

Both of these can have significant effects on a child's education

The Effects of Learning Disability and Autism on Education [1]

- Children or young people who have LD and Autism are aware of what goes on around them. However, their ability to **understand and communicate** may be limited, and they can find it hard to express themselves. **Speech problems** can make it even harder to make other people understand their feelings and needs.
- They can become frustrated and upset by their own limitations. When they **compare themselves** to other children, they can feel sad or angry and think badly of themselves.
- They may be **teased or bullied** at school.
- School can be a particular challenge for children with learning disabilities because of both the **learning** and **social** demands.
- Children who are able to cope comfortably with other people are likely to attend an ordinary/mainstream school, but have special forms of teaching. On the other hand, a child with a more severe disability may go to a **Special School**.
- For some children, a Statement of **Special Educational Needs and Disability (SEND)** will need to be prepared. This sets out what special help the child needs, and takes into account the views and wishes of the child and their parents.

The **Children and Families Act** [1] which came into effect in September 2014 introduced a broad definition of SEND, covering children and young people from 0-25 years of age. Where a child or young person has a disability or health condition which requires special educational provision to be made, they will be covered by the SEND definition.

For children with SEND, a disability or a complex health problem, early identification can help families to understand and support their children's emerging needs. Where identification is followed by early intervention and early support this may prevent the deterioration of conditions and help to improve outcomes for children's health and

well-being, safeguarding their development and supporting their educational attainment.

Key Definitions

- A child or young person has SEND if they have a learning difficulty or disability which calls for special educational provision to be made for them.
- A child of compulsory school age or a young person has a learning difficulty or disability if they:
  - Have a significantly greater difficulty in learning than the majority of others of the same age; or
  - Have a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions.
- A child under compulsory school age has special educational needs if they fall within the definitions above or would do so if special educational provision was not made for them.

Note - *The population of children with SEND is greater than the population of children with LD or Autism - not all children with SEND are disabled, and not all Disabled Children and Young People have SEND.*

Special Schools

A special school is a school catering for students who have special educational needs. Special schools may be specifically designed, staffed and resourced to provide appropriate special education for children with additional needs. Students attending special schools generally do not attend any classes in mainstream schools. Special schools with pupils aged 11 and older can specialise in 1 of the 4 areas of special educational needs [2]:

- Communication and interaction
- Cognition and learning
- Social, emotional and mental health
- Sensory and physical needs

Schools can further specialise within these categories to reflect the special needs they help with, for example Autism, visual impairment, or speech, language and communication needs.

Special schools in Bradford are as follows:

- 3 Primary
- 3 Secondary
- 1 Autism
- 1 Craven

Head teachers of these schools are part of the District Achievement Partnership (DAP). Partnership working through the DAP supports children and young people

with a range of SEND and focuses on ensuring the development of a cohesive, district wide approach to SEND

Outcomes

There are no specific national indicators in relation to children with SEN or disabled children but the following set by **Public Health England** are particularly relevant:

- School Readiness, including a good level of development in children at the end of reception and achieving the expected level in the phonics check in Year 1 (monitored by Public Health England)
- 16-18 year olds not in education, employment or training (monitored by Public Health England)
- Adults with a learning difficulty who live in stable and appropriate accommodation (monitored by Public Health England)

Guidance

NICE has released a number of documents which are particularly relevant to children and young people with LD/Autism and special educational needs:

- Public Health Guidance 20 - Social and emotional wellbeing in secondary education (2009)
- Clinical Guideline 128 - Autism spectrum disorder in under 19s: recognition, referral and diagnosis (2011)
- Public Health Guidance 40 - Social and emotional wellbeing: early years (2012)
- Quality Standard 48 - Depression in Children and Young People (2013)
- Clinical Guideline 170 - Autism spectrum disorder in under 19s: support and management (2013)
- Quality Standard 101 - Learning disabilities: challenging behaviour (2015)
- Clinical Guideline 158 - Antisocial behaviour and conduct disorders in children and young people: recognition and management (2017)

Education and Special Educational Needs in Bradford

> **Note:**
> – A comprehensive Health Needs Assessment of children with SEND was carried out in Bradford in 2015 and is currently being updated, this section reflects findings **up to** this point
> – This section describes SEND in Bradford as a global figure and will include some children who do not have Learning Disabilities or Autism as defined in Section 1)
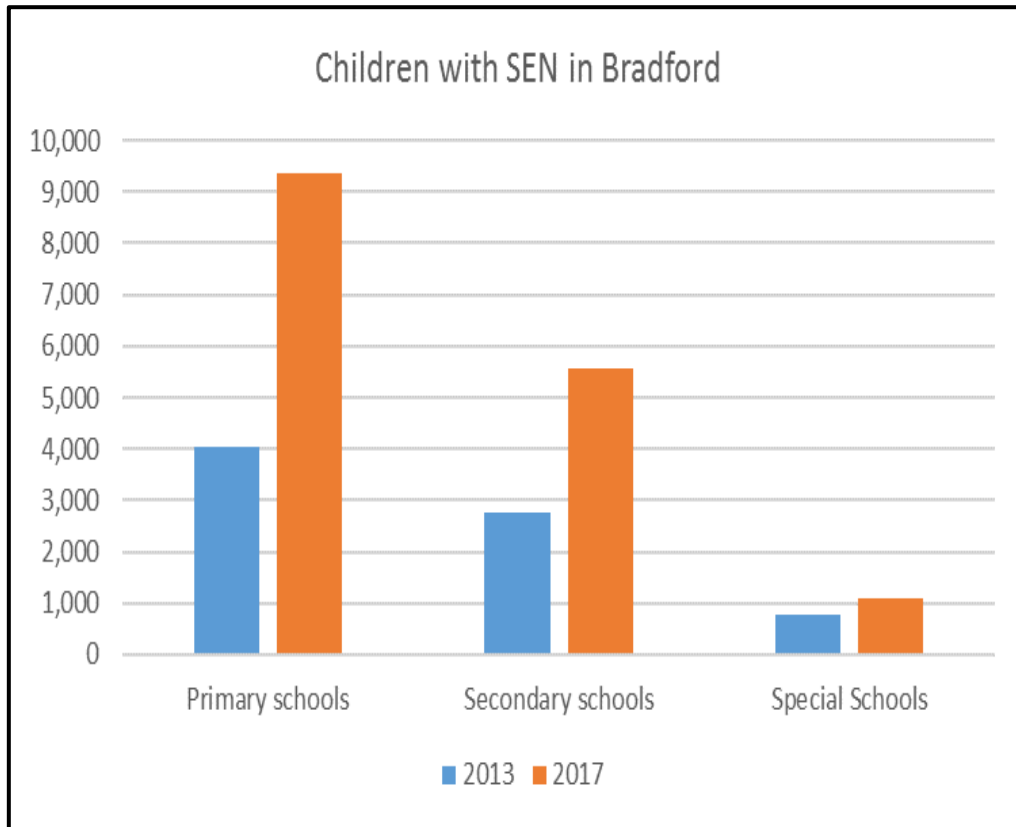
SEN - Key Statistics (Bradford JSNA)
- As at January 2017, there were approximately **16,500** children with SEND in primary, secondary or special schools in Bradford
- Over the period 2013-2017 the number of children with SEND in Bradford more than doubled from **7,950** to **16,486** (see Figure 1 below)
- A higher increase was seen in primary schools
- The 16,500 children with SEND in Bradford constitutes 16% of school aged children
- Over 80% of these are aged 5-15 years
- The majority are **White (49%)** or **Asian (42%)** (see Figure 2 below)
- Compared with national figures, Bradford has a **higher level of need**:
  - A larger proportion of children with SEND with severe learning disabilities, profound and multiple learning disabilities and physical disabilities
  - Higher rates of sensory problems, congenital anomalies and rare genetic abnormalities, all of which can contribute to the development of special educational needs
  - Although the District has higher levels of need, it has fewer children with Education Health and Care Plans,
- Of its children with SEND, Bradford has a higher proportion of children with Moderate LD than the average for England (see Figure 3 below)
- The number of children in special schools with a substantial amount of plaque is double that of those attending mainstream schools
- Children with SEND are more likely to have teeth extracted

Table 1 below sets out key SEND indicators for Bradford, Yorkshire and The Humber and England. Key observations include:
- A notably higher proportion of children with SEND and in Bradford compared with regional and national figures, sustained over the last 3 years
- Equally, this is reflected in the proportion of children receiving SEND support
- Bradford has a higher proportion of children with social, emotional and mental health needs than regionally or nationally, however this is not seen in special schools
- The proportion of pupils in Bradford special schools with speech, language and communication needs is notable lower than regionally or nationally

- A lower proportion of children with Autism in Bradford schools than regionally or nationally, except in special schools where this observation is reversed

Figure 1 **Children with SEND, by School Type, Bradford 2017**

Source: Department of Education 2017

Figure 2　　　　　　**Children with SEND by Ethnicity, Bradford 2017**

Source: Bradford JSNA 2017

Figure 3　　　　　　**Children with SEND by Type and Severity, Bradford 2017**

Source: Department of Education 2017

Table 1 Key SEND indicators for Bradford, Yorkshire and The Humber and England 2016-18

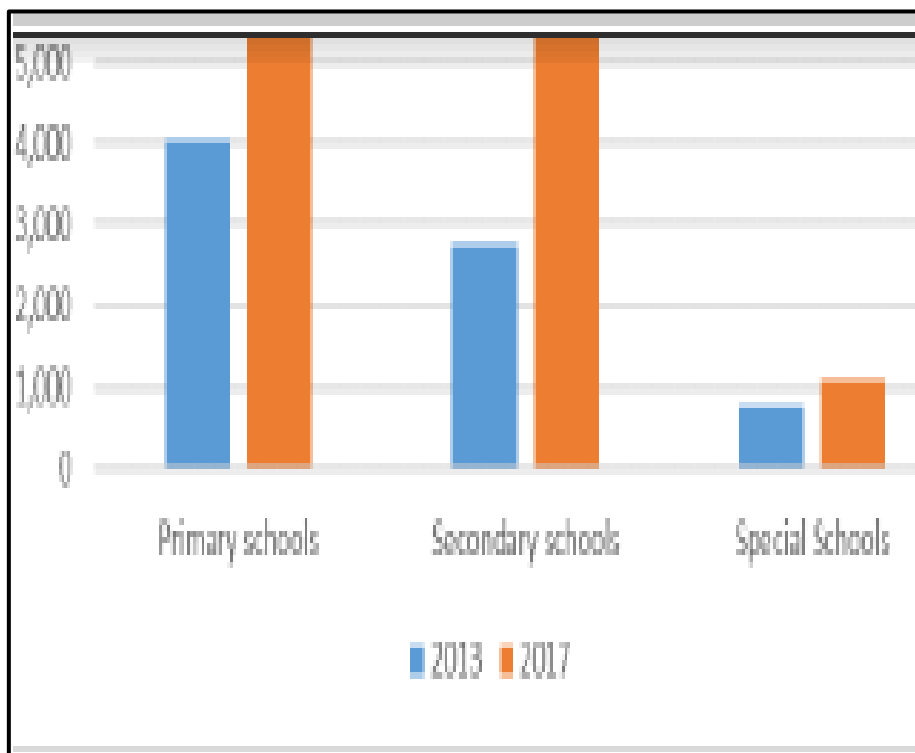| Indicator	Bradford	Yorkshire & Humber	England
% of pupils with a statement or EHC plan, based on where the child attends school (all schools)	2016 – 2.1% 2017 – 2.3% 2018 – 2.6%	2016 – 2.3% 2017 – 2.4% 2018 – 2.6%	2016 – 2.8% 2017 – 2.8% 2018 - 2.9%
% of pupils with SEN support, based on where the pupil attends school (all schools)	2016 – 13.9% 2017 – 13.6% 2018 – 13.6%	2016 – 11.6% 2017 – 11.6% 2018 – 11.9%	2016 – 11.6% 2017 – 11.6% 2018 – 11.7%
% of pupils with special educational needs, based on where the pupil attends school (all schools)	Pupils with statements or EHC plans 2.6% Pupils on SEN support 13.6% Total pupils with SEN 16.2%	Pupils with statements or EHC plans 2.6% Pupils on SEN support 11.9% Total pupils with SEN 14.5%	Pupils with statements or EHC plans 2.9% Pupils on SEN support 11.7% Total pupils with SEN 14.6%
% pupils with social, emotional and mental health needs in 2018	16.6% (state-funded primary school) 21.7% (state-funded secondary school) 8.7% (special school)	14.8% (state-funded primary school) 18.7% (state-funded secondary school) 11.6% (special school)	15.9% (state-funded primary school) 18.9% (state-funded secondary school) 12.6% (special school)
% pupils with speech, language and communications needs in 2018	30.9% (state-funded primary school) 8.3% (state-funded secondary school) 2.6% (special school)	29.6% (state-funded primary school) 9.4% (state-funded secondary school) 6.9% (special school)	29.8% (state-funded primary school) 11.3% (state-funded secondary school) 6.8% (special school)
% pupils with hearing impairment in 2018	2.6% (state-funded primary school) 3.6% (state-funded secondary school) 0.6% (special school)	2.2% (state-funded primary school) 3.2% (state-funded secondary school) 1.1% (special school)	1.7% (state-funded primary school) 2.3% (state-funded secondary school) 1.2% (special school)
% pupils with visual impairment in 2018	1.1% (state-funded primary school) 2.2% (state-funded secondary school) 1.2% (special school)	1.1% (state-funded primary school) 1.6% (state-funded secondary school) 0.6% (special school)	0.9% (state-funded primary school) 2.2% (state-funded secondary school) 1.2% (special school)
% pupils with multi-sensory impairment in 2018	0.1% (state-funded primary school) 0.1% (state-funded secondary school) 0.1% (special school)	0.2% (state-funded primary school) 0.1% (state-funded secondary school) 0.1 % (special school)	0.3% (state-funded primary school) 0.2% (state-funded secondary school) 0.2 % (special school)
% pupils with ASD in 2018	4.2% (state-funded primary school) 6.3% (state-funded secondary school) 32.1% (special school)	6.3% (state-funded primary school) 9.2% (state-funded secondary school) 27.7% (special school)	7.3% (state-funded primary school) 9.7% (state-funded secondary school) 28.5% (special school)
% pupils receiving SEN support but no specialist assessment of type of need	2.6% (state-funded primary school) 0.5% (state-funded secondary school) 0.0% (special school)	3.7% (state-funded primary school) 2.6% (state-funded secondary school) 0.0% (special school)	4.4% (state-funded primary school) 2.5% (state-funded secondary school) 0.1% (special school)

Transition

Children with a learning disability who are eligible for social care support can receive it until they become an adult, whereupon they transition to social care services designed for adults.

Transition for young people with LD and Autism to Adult Services remains a difficult process for everyone involved at different times: education, health and social care, as well as employment and housing. These service transitions take place before the background of significant biological and developmental changes for young people.

The needs of young people with Learning Disabilities and Autism during the time of transition vary considerably depending on the severity of their disability and the availability of social support they can draw on. There has been substantial research and policy around transition for young people over the last two decades. A sizeable number of transition studies has been conducted producing good evidence as to the needs of young people with regard to employment, education and health and social care [3].

An evidence review carried out in 2018 found that [3]
- The field of transition is marked by **service fragmentation**, differing eligibility criteria in the adult social care sector leading to a reduction of services for some young people and **underprepared or underfunded** adult specialist health care services which struggle to cater for the particular needs of this population
- It is widely felt that **joint clinics** between children's and adult health care providers are perceived as positive by young people and their families.
- Mental health provision for adolescents remains a persistent and serious service gap for young people with learning disabilities.
- The issue of continuity of care is often addressed by retaining young adults in child services in the NHS, in particular in specialist paediatric settings. This however creates issues around suitability of services and costs.
- Housing is the only domain that offers little robust published evidence on transition of young people with learning disabilities. There is some research around out-of-area placements and the impact of those on young people's pathways through education. However, the housing needs of young people and how to accommodate a growing young population with learning disabilities is currently not adequately reflected in research and evaluation studies.

Guidance

In 2016, NICE published:
1. NICE Guideline 43 - Transition from Children's to Adults' Services for Young People using Health or Social Care Services. Recommendations relevant to this report include:
    *   Consider establishing local, integrated youth forums for transition to provide feedback on existing service quality and to highlight any gaps. These forums should meet regularly, link with existing structures where these exist and involve people with learning disabilities
2. Quality Standard 140 - Transition from Children's to Adults' services, with the following Quality Statements:
    *   **Statement 1** - Young people who will move from children's to adults' services start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.
    *   **Statement 2** - Young people who will move from children's to adults' services have an annual meeting to review transition planning.
    *   **Statement 3** - Young people who are moving from children's to adults' services have a named worker to coordinate care and support before, during and after transfer.
    *   **Statement 4** - Young people who will move from children's to adults' services meet a practitioner from each adults' service they will move to before they transfer.
    *   **Statement 5** - Young people who have moved from children's to adults' services but do not attend their first meeting or appointment are contacted by adults' services and given further opportunities to engage.
3. The **Learning Disability Transition Pathway Competency Framework** [4] designed to:
    1. Identify things that people who provide LD services during transition need to know and do to ensure a smooth transition.
    2. Support:
        o   A well planned transition for young people
        o   Better understanding of the development needs of the workforce
        o   Effective training for those working with young people in transition
        o   The implementation of NICE Guideline 43

The Framework provides a **consistent quality standard** for the training and development of professionals who support young people in transition. The framework can also improve efficiency across organisations through a consistent approach to staff development; a focus on person centred care and better joined up working between agencies.

Note - In 2007, the Department of Health issued "A transition guide for all services - key information for professionals about the transition process for disabled young people" [(x)], this is not explored in detail here.

Transition in Bradford

Transition for people with LD and Autism can involve the migration from SEN support to Education, Health and Care (EHC) support. An **Education, Health and Care Plan** (EHCP) is available for children and young people aged **up to 25** who need more support than is available through SEN support. EHCPs identify educational, health and social needs and set out the additional support to meet those needs. **A considerable and complex programme was established in 2018 to develop a <u>Bradford Integrated Transitions Policy</u> to support integration and maximise outcomes** (further description is beyond the scope of this report)**.**

In Bradford, following eligibility screening by an EHCP Panel, Transitions are overseen by a **Transitions Team** which provides advice, information; assessments, support planning, case coordination and reviewing services to young people aged 14 to 25 transitioning into adulthood and their parents/carers. The team aims to promote a strength-based approach to maximise independence into adulthood, supporting young people to be aspirational about their future.

Young people are eligible for consideration for a service from the Transitions Team when they:
- Have an EHCP or identified need for an EHCP
- **Are aged between 14 and 25 at the time of referral and have still to transition into Adults Services**
- Their needs cannot be meet via advice and information or early interventions and support offers
- Have a severe or profound learning disability
- And or a severe or profound physical disability
- And or a significant sensory impairment
- And or a progressive conditions and complex medical needs
- Autism Spectrum Disorder with a learning disability or other complex health needs.
- Autism Spectrum Disorder with no other needs, in an advisory capacity from age 14 and to commence care act assessment from age 17.
- A combination of disabilities, which individually are not severe but collectively cause as much impact as a severe disability

The Transitions Team works closely with parents and carers including liaison with Parents forums and advisory services to ensure parents and carers are kept fully involved and informed about Transition's pathways and specifically about the young person they are involved with. The Transition Team also engages with Education to

ensure the EHCP becomes a more comprehensive document with appropriate social care information included in young peoples' EHCPs.

Additionally, The CCGs fund **Transition Nurses** based within local care trusts to support young people as their health services change from the familiar arrangements of childhood into **GP led adult health provision**

Activity

- There is currently **1,400** young people aged 14-25 with EHCP who are considered as having SEND (not all have LD and Autism)
- The Transition Team currently supports **453** young people with SEND
- **386** cases are allocated, **124** within Children's Services and **262** within Adults
- The remaining **67** are either being screened or waiting for allocation
- An additional **16** young people have a transitions worker as a named worker

(Note there is also transition support available through CAMHS and at St Luke's Hospital)

What Does This Mean for People with Learning Disabilities and Autism in Bradford?

The education years are a key time for children with LD and Autism, and they may be vulnerable to bullying and stigma which can adversely affect their development and quality of life. The transition period is of particular importance, as it is the period where much of the quality of adult life will be established through growth of independence and the opportunity for fulfilling employment. This report has found that the structures and processes underpinning education and transition are complex and could benefit from a structured programme approach and a composite reporting method. Equally, a review of resources may be helpful as we plan for coming years

---

Strategic Recommendations

1. Consideration should be given to adopting a formal programme management approach to education and transition
2. A review of resources should be a central part of this process
3. A focused workstream should be established to review the nature of integration between education and social work sectors
4. A planned educational event for young people and carers should take place early in 2019 to follow on form the 2018 event for professionals

---

REFERENCES:
1. The Child with General Learning Disability: for Parents and Carers. Royal College of Psychiatrists. 2017.
2. https://www.gov.uk/types-of-school (accessed 28/01/19)
3. Kaehne A, Kiernan J, Ridley J. Rapid Review - Transition for young people with Learning Disabilities in Housing, Social Care, and Health Care, Education/Training, and Employment. Evidence-Based Practice Research Centre, Edge Hill University. 2018.
4. https://www.hee.nhs.uk/our-work/learning-disability (accessed 28/01/19)

Section 14 – End of Life Care and Palliative Care

End of life care should help people to live as well as possible until they die and to die with dignity, with EOLC patients being defined as 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) [1]. End of life care includes **palliative care** which makes people as comfortable as possible, by managing pain and other distressing symptoms. It also involves psychological, social and spiritual support for patients and their family or carers in a holistic approach, dealing with you as a "whole" person, not just the illness or symptoms. Palliative care is not just for the end of life, it may be needed earlier in an illness, while patients are still receiving other therapies to treat their condition.

Inequalities in End of Life Care

In May 2016 the Care Quality Commission (CQC) published a thematic review into inequalities in end of life care [1]. The review identified that 'people from certain groups in society sometimes experience poorer quality care at the end of their lives because providers do not always understand or fully consider their needs'. **It identified people who have a learning disability as one such group**. The Confidential Inquiry into premature deaths of people with a learning disability (CIPOLD) found that for many people with a learning disability, who were dying, end of life care was not coordinated and the support for the person and their families could have been improved [3]. It also identified that **people with a learning disability were less likely to have access to specialist palliative care services and opioid analgesia than a comparison group of people without a learning disability**. Other research has suggested that hospice, palliative care and end of life care professionals report limited contact with people with learning disabilities and a lack of confidence in working with this group and understanding their needs [4].

1. <u>EOLC in Learning Disability</u>

In respect of mortality, there are many well know associations such as Down's syndrome where thyroid or hole-in-the-heart problems can lead to younger death, although dementia is the commonest cause of death, occurring later in life. Two, possibly preventable causes of death in LD stand out as particularly important because they a common and affect most groups of people with learning disabilities [5]. These are:

- dysphagia and lung problems caused by solids or liquids going down the wrong way leading to aspiration pneumonia (14% of deaths *where a condition associated with learning disabilities are reported*)
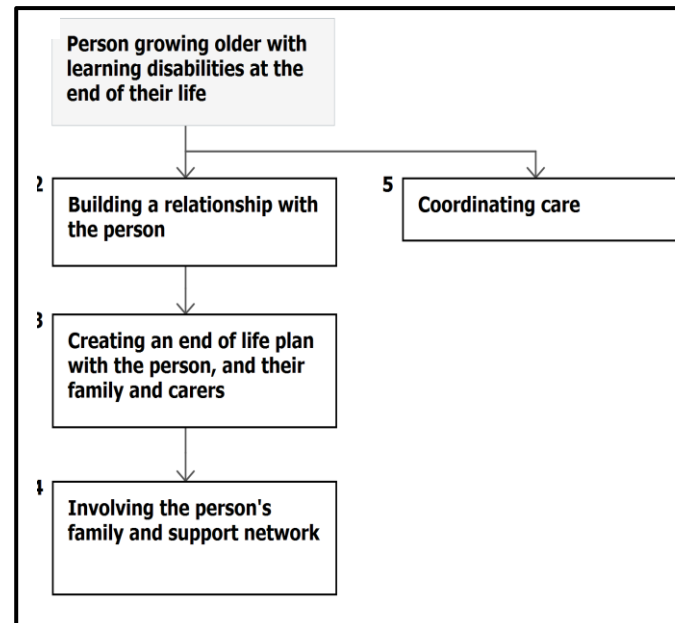- Epilepsy or convulsions (13%).

National Guidance

NICE National Guideline 96 - Care and Support of People Growing Older with Learning Disabilities [6], makes explicit recommendations in respect of the end of life care of people with LD. Examples of these being:

- Maximising access to end of life care services
  Give people growing older with learning disabilities and their family members, carers and advocates accessible, timely and person-centred information about all the potential care options available for end of life care, including hospice services.
- Making sure end of life care is person centred
  Practitioners providing end of life care should:
    - Spend time getting to know the person to understand their needs
    - Identify who the person would like to involve in creating their end of life plan and include the person themselves and everyone who supports them in discussions and planning.
    - Ask the person regularly who they would like to involve in discussions about their end of life plan and make it possible for them to die where they wish
- Involve families and support networks
    - Learn from family members, carers or advocates about the person's needs and wishes, including those associated with faith and culture, nutrition, hydration and pain management
    - Mainstream end of life care services should make reasonable adjustments to support the person, their family members, friends and carers and other people they live with, throughout palliative and end of life care and bereavement
- Staff skills and expertise for supporting end of life care

- Commissioners and providers of end of life care should recognise the complex needs of people with learning disabilities. They should provide ongoing training for staff to ensure they have the expertise to provide good-quality coordinated care, enabling people to die in their own home or another place of their choice.

NICE has also produced an end of life pathway for people with LD (below)

In 2017, NHS England published *'Delivering high quality end of life care for people who have a learning disability - Resources and tips for commissioners, service providers and health and social care staff'* [7]. This guide provides a framework for improving practice and outcomes in end of life care based on 6 key Ambitions, these being:

1. Ambition 1 **'Each person is seen as an individual'**
2. Ambition 2 **'Each person gets fair access to care'**
3. Ambition 3 **'Maximising comfort and wellbeing'**
4. Ambition 4 **'Care is coordinated'**
5. Ambition 5 **'All staff are prepared to care'**

6. Ambition 6 **'Each community is prepared to help'**

Under each ambition, those commissioning, providing or delivering care to people with a learning disability at the end of their lives will find 'top tips', resources and good practice examples to support the achievement of each ambition for people with a learning disability.

1. <u>Palliative Care in Autism</u>

Providing a thorough palliative care assessment for people with autism and delivering needed services is often an immense undertaking that can be quite stressful for all involved in care. The healthcare experience for all three stakeholders - patient, family, and medical providers, presents unique challenges; however, positive results can be obtained with **advanced planning** [8]. Fortunately, a comprehensive guide to EOLC in people with Autism was published in 2016 by Scottish Autism [9]. The publication focuses on four key areas of support at end of life:

- Physical
- Psychological
- Social
- Spiritual.

For people on the autism spectrum there is a requirement for support and accommodations from diagnosis through to end of life that are particularly person-centred and inclusive of the diversity of needs in a broad and varied spectrum of individuals. For example:

- Difficulty accessing equitable and appropriate health care
- Social communication and understanding difficulties that may affect how they form and sustain a network of social support
- Differing perspectives and thinking styles may affect the way they understand their illness and express how they feel
- A definition of meaning and spirituality that may be deeply personal
- Struggling to place themselves in the narrative of their life

In addition, the report proposes a Top 5 tips on providing palliative care to a person on the autism spectrum

1. **Ensure that the person is involved in decisions about their care.**

For people on the autism spectrum who have differing communication preferences and ways of processing information, changes to how we present information and choices to them can have a significant effect on their capacity to make decisions about their care.

It is always important to consider: does the person lack capacity to make a decision about their care, or have we failed to make changes and put in the correct supports to enable them to understand their choices and make informed decisions?

If an individual does not have the capacity to enter into a process of advance care planning then every effort should still be made to determine their wishes.

2. **Consistency of support and strong partnership working between health and social care teams is essential.**

It is vital that social care staff and healthcare professionals work closely together to provide the best possible care for the person with a life-limiting illness.

Uncertainty over roles and poor communication can contribute to a breakdown in partnership working. Regular discussion forums and team meetings provide supportive spaces for everyone involved in the person's care to ask questions that contribute to a greater understanding of the person's needs and wishes.

3. **Plan and communicate to health teams what reasonable accommodations or adjustments might have to be made to ensure best possible quality of palliative and end of life care.**

For individuals who struggle to effectively communicate their needs, healthcare and communication passports can provide valuable and important information to ensure best possible person-centred care and treatment.

Management of pain is a particularly important part of end of life care and is dependent on the person being able to communicate how they feel and be descriptive of pain. For those individuals who struggle to express themselves, scales for expressing pain and

pain assessment tools (such as the DisDAT Disability Distress Assessment Tool) should be used to document indicators of distress and discomfort.

4. **Understanding the thinking style of the person you are supporting enables you to plan and prepare for difficult conversations and consider how information is best communicated.**

When a person on the autism spectrum we are supporting receives such life changing news we should take time to stop and understand:
- How does the person think about and experience the world around them
- How do they learn and take in new information
- What is important to them in their life.

The answers to these questions can be used to:
- Tailor information and communication to be reflective of the person's thinking and learning style
- Motivate engagement in important discussions, and support understanding by making information relatable
- Prioritise the information being communicated based on the person's needs, and not what we presume is appropriate based on our own feelings and experiences

5. **Support the person to reflect on important events in their life, and experiences that have given their life meaning.**

These reflections can be captured in different ways. It might be important to utilize a range of formats or multi-sensory tools to engage and evoke memories. In addition to use of pictures and words it might be useful to include tangible objects of reference, audio, scents, textures or video.

2. End of Life Care for People with Learning Disabilities in Bradford

Table 1 below shows the number of patients who died who have been known to local specialist palliative care services (they are recorded on SystmOne as LD Cluster)
There are some other LD patients – <5 active patients and 7 patients who have been discharged over the last 4 years but who are still alive
Anecdotal evidence locally suggests that there are patients seen in EOLC services with LD/Autism who are not officially recorded as having either condition

Table 1 Patients in Specialist Palliative Care Recorded having LD/Autism, Bradford 2013-18

Year	Number
2013	8
2014	16
2015	23
2016	18
2017	14
2018	17 to date

Since the 1990s, there have been a number of reports and case studies which have

consistently highlighted that, in England, people with learning disabilities die younger than people without learning disabilities. The Confidential Inquiry of 2010-2013 into premature deaths of people with learning disabilities (CIPOLD) reported **that for every one person in the general population who died from a cause of death amenable to good quality care, three people with learning disabilities would do so** [3].

In the last 5 years (2013– 17) for main underlying cause of death, there are <5 deaths recorded as being due to from LD, and <5 due to Autism in the last 5 years. Looking at all cause of death fields, there are a total of 27 deaths where LD is recorded over this time period:

2013: 7
2014: 5
2015: 6
2016: 5
2017: <5

For Autism there were **<5 deaths recorded in the last 5 ye**ars (1 in 2015, 1 in 2014 and 2 in 2013). These figures strongly suggest an under-recording of LD and Autism in death certificates.

What does This Mean for People with LD or Autism in Bradford?

In the first instance it is encouraging that our local EOLC services provide specialist EOLC and Palliative Care to people with LD and Autism, and also that these are recorded and audited. What is of concern is the rate at which people with LD/Autism are accessing this care. As noted above, it is known that there is a significant inequality across the country in this respect.

No person should die without EOLC and palliative care should they require it. A path to a solution is suggested in the reporting figures above that make it clear that reporting and coding of LD/Autism in Bradford is not sufficient to sustain an acceptable level of access – this is not unique to Bradford by any means, Other studies have shown that **only about four out of ten death certificates for people with learning disabilities record this problem** [5]. This issue must be addressed in a partnership fashion as LD/Autism signs and symptoms present to a range of services, including Primary Care, Secondary Care and Social Care.

> **Strategic Recommendation**
>
> **A partnership workstream should be established to review and audit the coding and recording of LD and Autism in mortality and EOLC. This should then inform a wider initiative to ensure that advanced planning for EOLC is available to all people with LD and Autism.**

REFERENCES:

1. Quality Standard 13 - End of Life Care for Adults. National Institute for Health and Care Excellence. 2011.
2. A Different Ending - Addressing Inequalities in End of Life Care. Care Quality Commission. May 2016.
3. Heslop, P. et al., 2014. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. The Lancet, 383(9920), pp.889–895.
4. The Route to Success in End of Life Care - Achieving Quality for People with Learning Disabilities. NHS England.
5. Glover G, Ayub M. How People with Learning Disabilities Die. Learning Disabilities Observatory. 2010.
6. National Guideline 96. Care and Support of People Growing Older with Learning Disabilities. National Institute for Health and Care Excellence. 2018.
7. Delivering High Quality End of Life Care for People who have a Learning Disability - Resources and Tips for Commissioners, Service Providers and Health and Social Care Staff. NHS England. 2017.
8. Williams, C. & Atmore, K., 2016. Palliative Care for Children with Comorbid Autism Spectrum Disorders (FR473). Journal of pain and symptom management, 51(2), pp.375–376.
9. Palliative and End of Life Care for Autistic People. Scottish Autism. 2016.

Section 15 - Outcomes

One of the key elements of the changes in health and social care over the last five years has been a firm sharpening of the focus on *outcomes* as opposed to process and activity measures ('outputs'), largely underpinned by the realisation that to deliver truly patient-centred care we must focus on what matters most to the patient and their carers. This section aims to explore outcomes at a commissioning/administrative level rather than the individual level.

The publication of three key outcomes frameworks for health and social care has demonstrated this commitment nationally. The three outcomes frameworks are:
- The Public Health Outcomes Framework
- The Adult Social Care Outcomes Framework
- The NHS Outcomes Framework

The outcomes frameworks set out high level areas for improvement, alongside supporting indicators, to help track progress without overshadowing locally agreed priorities They help to ensure that common challenges are highlighted at the local level across the health and care system, informing local priorities and joint action, whilst reflecting the different accountability mechanisms in place.

The three outcomes frameworks are together intended to provide a focus for action and improvement **across the system**. Each of the outcomes frameworks include the main outcomes that represent the issues across health and care that matter most to all of us.

What are outcomes?
Conventional health and wellbeing commissioning and contracting have tended to be preoccupied with outputs/activity, such as the number of contracts with patients or service users, whether waiting times are met, the number of complaints received and the hours services are offered for. Although many of these indicators are important, they do not answer the most meaningful question of all, which is what is achieved for service users - the term can generally be thought in this context as referring to the impact health and social care activities have on people — on their lifestyle, symptoms, ability to do what they want to do, their quality of life and ultimately on whether they live or die.

In theory, outcome based commissioning should focus not on activities and processes but on results. For example, rather than aiming to ensure that *"our LD service sees 50 patients per week"*, we could aim to have *"50 people diagnosed with Learning Disability, given appropriate advice and support and have management plans agreed and communicated to the person and their carers"*.

So, the point of an outcomes-based approach is to shift the primary focus from how a service operates (what it does) to the good that it accomplishes (what it achieves) – being careful to maintain the quality of the processes as we do so.

For the purposes of the Health Needs Assessment, the outcomes planned for different people served by health and social services are likely to be different. In broad terms they will fall into two categories:
- **Maintenance outcomes**, for example to enable someone with dementia to continue living at home despite their condition worsening or a reduction in carer support
- **Change outcomes**, such as where someone with dementia experiences improvements in the quality of their life which leads to greater community involvement and/or less dependency on services.

Outcomes can be further categorised into:
1. **Individual** outcomes - e.g. a patient with dementia now gets up in the mornings without staff support
2. **Service level** outcomes - e.g. social services supported 10 carers to access the correct benefits
3. **Strategic** outcomes - e.g. more people with dementia were helped to remain living at home

What are the Key Outcomes for Learning Disability and Autism?

Public Health Outcomes Framework

Domain 1 - Improving the wider determinants of health
- 1.06i - Adults with a learning disability who live in stable and appropriate accommodation

- 1.06ii - Adults in contact with secondary mental health services who live in stable and appropriate accommodation
- 1.08ii - Gap in the employment rate between those with a learning disability and the overall employment rate
- 1.18i - Social Isolation: percentage of adult social care users who have as much social contact as they would like
- 1.18ii - Social Isolation: percentage of adult carers who have as much social contact as they would like

Domain 2 – Health Improvement
- 2.08ii - Percentage of children where there is a cause for concern

Adult Social Care Outcomes Framework

Domain 1 – Enhancing quality of life for people with care and support needs
- 1B - Proportion of people who use services who have control over their daily life
- 1C - Proportion of people using social care who receive self-directed support, and those receiving direct payments
- 1D - Carer-reported quality of life
- 1E - Proportion of adults with a primary support reason of learning disability support in paid employment
- 1J - Adjusted Social care-related quality of life – impact of Adult Social Care services
- 1G - Proportion of adults with a primary support reason of learning disability support who live in their own home or with their family

Domain 2 – Delaying and reducing the need for care and support
- 2A - Long-term support needs met by admission to residential and nursing care homes, per 100,000 population

Domain 3 – Ensuring that people have a positive experience of care and support
- 3A - Overall satisfaction of people who use services with their care and support
- 3B - Overall satisfaction of carers with social services
- 3C - The proportion of carers who report that they have been included or consulted in discussion about the person they care for
- 3D - The proportion of people who use services and carers who find it easy to find information about support

Domain 4 – Safeguarding adults whose circumstances make them vulnerable and protecting from avoidable harm
- 4A - Proportion of people who use services who feel safe
- 4B - Proportion of people who use services who say that those services have made them feel safe and secure

NHS Outcomes Framework

Domain 1: Preventing people from dying prematurely
- 1.7 - Excess under 60 mortality rate in adults with a learning disability

Domain 2 - Enhancing Quality of Life for People with Long-term Conditions
- 2.4 - Health-related quality of life for carers

Domain 4: Ensuring that people have a positive experience of care
- 4.6 - Bereaved carers' views on the quality of care in the last 3 months of life

What Does This Mean for People with Learning Disabilities and Autism in Bradford?
The national outcomes frameworks provide a broad scope from which to draw a measurement and monitoring process suitable for the Transforming Care Programme in Bradford.

Strategic Recommendation
1.The Transforming Care Programme Board should agree a set of indicators from the national outcomes frameworks and put in place a monitoring process to inform performance and progress over coming years.

Section 16 – Corporate Needs Assessment

This part of the HNA is designed to achieve two key objectives:
1. To capture the insights and opinions of key stakeholders in a meaningful and understandable way that can be used to contribute to the conclusions and recommendations.
2. To describe local services that apply to people with LD and Autism and their carers

Methodology

In order to undertake this section of the report, discussions were held with stakeholders relating to each section of the report. In addition, key stakeholders were contacted and asked to take part in an interview which would:
1. Give them the opportunity to communicate their experience and knowledge in a manner which would contribute to the findings of the HNA.
2. If they were a service provider, involve a number of questions specific to their service being asked, and they may be asked to provide some data on service activity where appropriate.

The Interview

Interviews were conducted one on one, with the exception of focus groups, and each took around 30 minutes in total. Audio recordings were not made.

The interview consisted of five questions, which were discussed in a 'semi-structured' manner, where the responses were allowed to progress freely and cross over to other subjects with follow up questions introduced as the interviewer or interviewee felt appropriate. The same five questions were asked of all interviewees, as follows:

1. **What comes to mind when you think of LD and Autism in Bradford?**

    This question was included in order to try and build up a more complete understanding of the different factors affecting LD and Autism and its management across the District. It was often described to interviewees as identifying a Bradford 'flavour', where there might be elements particular or specific to Bradford, which would help to underpin the findings of the HNA. In particular, are there specific cultural aspects, including organisational and professional cultures that are important, and that could help direct the subsequent questions.

2. **What do you think is the biggest challenge we face in respect of LD and Autism in Bradford?**

The purpose of this question was to develop an understanding of the 'big issues', which would prove important when the project reached the stage of formulating recommendations. This was a key question in terms of identifying recurring themes where repeated interviewees identified the same issues repeatedly. In addition, this question was key in helping to identify issues which had not been previously thought of and which had not come up in other interviews. This question also served as a useful way of helping the interviewee to begin thinking about their priorities, particularly with a view to questions 4 and 5.

3. **What do you think is the biggest asset we have in Bradford in respect of LD and Autism?**

The 2010 LGA report 'A Glass Half Full' highlighted the opportunities available through using an 'asset approach' in health and social care, by identifying the capacity, skills and knowledge present in individuals, communities and organisations and maximizing their potential to contribute to improvements [1]. This question was designed to reflect this approach and to ensure that the resources already present in Bradford and Airedale are reflected in this piece of work.

4. **What is the single most important priority for action currently in respect of LD and Autism in Bradford?**

This question was couched as being partnered with question 5, although the nature of question 5 was not revealed. This question was designed to get the interviewee to commit to a single strategic or operational priority above all others, hopefully informed by their responses to the first three questions. Whilst it is recognized that priorities are rarely addressed in isolation, it was hoped that this question would help to underpin the recommendations which would follow at the end of the HNA.

5. **If you had £1,000,000 to spend to achieve the answer set out in question 4., how would you spend it?**

It was explained to interviewees that, having identified their key priority for action, it would be helpful if they could outline how this might be achieved in practice. Hence, a notional sum of £1,000,000 was offered and the interviewees asked how they would spend this to achieve their priority. It was hoped that responses to this question might also help in the design of future business cases.

Interviews

Interviews were conducted by a Consultant in Public Health and the Clinical Lead for LD and Autism.

Interviewees were selected to reflect the stakeholder profile and to include representation from key service providers and those who hold significant datasets relating to LD and Autism in the District.

Focus Groups with people with people with LD and Autism and their carers were arranged by the Clinical Lead and held at the Waddiloves Centre.

Patient and Public Perspectives

Service users' and carer perspectives were gathered from the following;

1. National and local reports that specifically gathered views and needs of those with LD and Autism or from those caring for people with LD and Autism.
2. Face to face meetings with individuals and organisations working directly with people with LD and Autism and their carers.
3. Focus groups with those with LD Autism and their carers as highlighted above.

A list of those who contributed to the corporate needs assessment is set out in table 1 below, with those who took part in the qualitative exercise highlighted in yellow.

Table 1   **Contributors to Corporate Needs Assessment**

Name	Role	Organisation
Jackie Armitage	Learning Disability Matron	Bradford District Care Trust
Jo Butterfield	Project Lead	West Yorkshire Integrated Care System
Anne Connolly	General Practitioner	Bevan Healthcare
Victoria Donnelly	Clinical Lead for Learning Disabilities	Bradford District Care Trust
Cllr Sue Duffy	Local Authority Councillor	City of Bradford Metropolitan District Council
Ali Jan Haider	Director of Strategic Partnerships	Bradford District Clinical Commissioning Group
Mike Halliday	Commissioning Manager	Bradford District Care Trust
Professor Chris Hatton	Professor of Public Health and Disability	Lancaster University
Lorraine Hawkesworth-Quill	Service Manager	City of Bradford Metropolitan District Council
Ruth Hayward	Head of Commissioning (Childrens)	Bradford District Clinical Commissioning Group
Sherie Herpe	Matron	Airedale NHS Trust
Helen Hirst	Chief Officer	Bradford CCGs
Dr Mike Hughes	Consultant in Palliative Medicine	Manorlands Hospice
Bharti Kaur	Housing Project Manager	City of Bradford Metropolitan District Council
Linda Lynch	Performance Analyst	City of Bradford Metropolitan District Council
Kurt Maloney	Team Lead Dietician - Learning Disabilities	Bradford Teaching Hospitals Foundation Trust
Iain Maxwell	Quality Assurance Officer	Bradford CCGs
Angela Moulson	GP Mental Health Lead	Bradford District Clinical Commissioning Group
Mairead O'Donnell	Head of Commissioning - Learning Disabilities	City of Bradford Metropolitan District Council
Andrea Richards	Safeguarding Manager	City of Bradford Metropolitan District Council
Helena Rolfe	General Practitioner	Ilkley Moor Medical Practice
Ruksana Sardar-Akram	Senior Public Health Manager	City of Bradford Metropolitan District Council
Tony Sheeky	Commissioning Officer	City of Bradford Metropolitan District Council
David Sims	Consultant Psychiatrist	Bradford District Care Trust
Lyn Sowray	Assistant Director - Social Care	City of Bradford Metropolitan District Council
Sally Townend	Service Manager - Transitions	City of Bradford Metropolitan District Council
Sarah Turner	Named Nurse - Safeguardung Adults	Bradford Teaching Hospitals Foundation Trust
Toni Williams	Consultant in Public Health	City of Bradford Metropolitan District Council

Analysis

The interviews were analysed using basic qualitative techniques which have been well recognised in healthcare research [2, 3, 4]. This took place as follows:

1. Transcripts of the interviews were read through several times and the subjects identified were organized and sorted in order to provide a basis for identifying themes (a process called coding)
   a. **Recurrent themes** - those that were mentioned by three or more interviewees, as this number was felt to represent sufficient triangulation
   b. **Major themes** – these were developed where clear groups of recurring themes could be identified. Those themes can be considered particularly important in respect of the influence they would have on our understanding of LD and Autism in Bradford and Airedale and were the most important to the study's aims

The focus groups were analysed separately as it was felt that recounting what was said in a more narrative manner would be more powerful and that this approach lent itself better to the focus groups than the analytic approach used in the other stakeholder interviews. In particular it was felt that the focus groups would provide a valuable comparison with the findings of the qualitative analysis and would help to place these in context and provide validation or otherwise.

Results

In total 14 individual qualitative interviews took place and two focus groups comprising patients and carers.

Themes identified comprised:
- 10 recurrent themes
- 3 major themes

Major Themes
1. Mainstream services are not inclusive/equipped or able to manage people with LD and Autism
2. People with LD and Autism and their carers, along with staff who manage LD and Autism as the key asset in the District
3. The system is chaotic and not joined up

Recurrent Themes

1. Inadequate resources to manage need
2. Lack of local expertise, particularly in Autism care
3. Dependence on carers to provide key support
4. Long waiting list for assessments in Autism
5. Lack of awareness among the public and health social care staff
6. Need for a central resource/unit as a focal point and single point of access
7. Need to spend money more smartly
8. No idea of the numbers of people with diagnosed and undiagnosed LD and Autism
9. Reduction in funding and resource as educational psychologists have been replaced by a trading service
10. Disconnect between adult and children's services

Focus Group Analysis

Focus Group 1

Group size: 3 people with LD

Format: Semi-structured group discussion based around the 5 pre-selected
                    Questions

Responses:

1.   **What comes to mind when you think of LD and Autism in Bradford?**
- Fighting for support
- Lack of information
- "People don't always understand"
- Lack of resources for people to access, e.g. sensory rooms

2.   **What do you think is the biggest challenge we face in respect of LD and Autism in Bradford?**
- General public can be ignorant about Learning Disabilities
- Lack of flexibility in Primary Care

- Only getting socal support when in crisis
- Need more occupational and employment support

3. **What do you think is the biggest asset we have in Bradford and Airedale in respect of LD and Autism?**
   - Waddiloves
     - Flexility of appointments
     - Seen fast
     - Reasonable adjustments
   - "Telemedicine was great"

4. **What is the single most important priority for current actions in respect of LD and Autism in Bradford?**
   - Raising awareness of what people with LD and Autism are capable of
   - More employment opportunities, particularly in stimulating jobs
   - More flexibility in support options

5. **If you had £1,000,000 to spend to achieve the answer set out in question 4 above, how would you spend it?**
   - More activities – support to have an active life
   - Sensory support and rooms
   - Expansion of the Waddiloves service

Focus Groups 2 and 3

Group size: 12 family carers, 4 people with LD and 3 support staff from local provider units split between groups 2 and 3

Format: Semi-structured group discussion based around the 5 pre-selected
             Questions

1. **What comes to mind when you think of LD and Autism in Bradford?**
   - Mainstream health services don't make adjustments
   - The cost of doing things, plus charges

- People living longer and need for services to adapt to this
- Nowhere for people to go to when they leave home
- Importance of Waddiloves

2. **What do you think is the biggest challenge we face in respect of LD and Autism in Bradford?**
- Where do children go after transition?
- Difficulty fitting in due to different behaviours
- Cost of placements and impact of this on carers
- Not enough adult respite staff
- "Hospitals don't understand" – difficult to get right support

3. **What do you think is the biggest asset we have in Bradford in respect of LD and Autism?**
- Waddiloves
- Support from Waddiloves nurse when in hospital
- Involvement of families in planning

4. **What is the single most important priority for current actions in respect of LD and Autism**
- More services for people with behavioural issues
- More sensory provision
- Better training services
- Central point of access
- Respite remaiing in Bradford

5. **If you had £1,000,000 to spend to achieve the answer set out in question 4 above, how would you spend it?**
- A Carers Hub
- Sensory support and rooms
- Support for people with LD/Autism and Dementia

What Does This Mean for People with Learning Disabilities and Autism in Bradford?

This is a particularly significant section of the HNA as it is crucial to gain the insights of people who work across the "system" and, in particular those who use it.

We would like to thank all who took part in this section of the report and those who helped to facilitate the focus groups.

There is a huge amount of information contained within this section, and its use should be approached carefully and systematically. It is important that quotes and summary sections are not used in isolation unless discussions take place with those who produced this report.

<u>Strategic Recommendations</u>

1.The Transforming Care Programme Board should lead work to ensure that the information provided in this section is made available to commissioners, providers and all those involved in planning LD and Autism services

2.The use and application of the information contained here should be taken through members of the Transforming Care Programme Board

3.The Transforming Care Programme Board should continue to support the Waddiloves Health Centre in developing this work

---

REFERENCES:

1. A Glass Half-full: How an Asset Approach can Improve Community Health and Well-being. Improvement and Development Agency 2009
2. Pope C, Mays N. Critical reflections on the rise of qualitative research. BMJ. 2009 Sep 15;339(sep15 2):b3425–5.
3. Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. BMJ. 2000 Jan 8;320(7227):114–6.
4. Pope C, Mays N. Qualitative Research: Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. BMJ. 1995 Jul 1;311(6996):42–5.

Appendix 1 - Overview of examples of systematic reviews assessing the effectiveness of interventions to improve the health of people with a learning disability – Derived form Cornwall Council LD Health Needs Assessment with Thanks to Richard Sharpe

-								
Summary of interventions reported by systematic reviews and meta analyses								
Category	Author, year, location of corresponding author	No. of included studies, No. from the UK	Quality of included studies	Population	No. of RCT included	Type of interventions included	Outcome/s of interest	Summary of main finding/s
Health checks	Robertson et al. (2014), UK	45 & 43 from the UK (19 from England)	Not assessed. All studies considered regardless of quality	All age groups	None	Health checks	Health conditions, resultant health actions, health gains, perceptions, impact on social care staff & healthcare, gaps / barriers & cost	Health checks are effective; in identifying a wide range of previously unidentified conditions (minor through to serious & life threatening); targeting actions to address health needs; and may not be associated with higher health service usage costs. However, the suggestion that health checks may reduce future health costs remains untested
Lifestyle	Brooker et al. (2015), only abstract available	6 & not reported	Poor	-	-	health education or health promotion programs with PA, nutrition, and weight loss components	Improved involvement in physical activity	Some limited evidence that physical activity interventions may improve health and well-being. Given the health inequities that exist, there should be efforts to improve PA levels among this group

Category	Author, year, location of corresponding author	No. of included studies, No. from the UK	Quality of included studies	Population	No. of RCT included	Type of interventions included	Outcome/s of interest	Summary of main finding/s
								Summary of interventions reported by systematic reviews and meta analyses
	Willems et al. (2017), Netherlands	45 & not reported	Low quality, but 10/13 RCT studies were of medium to high quality	All age groups	13	Behavioural change techniques (BCT)	To improve lifestyle interventions for physical activity, nutrition or both	Interventions used at least one BCT. The three categories of studies all frequently used 'Provide information on consequences of behaviour in general' (n = 27) and the 'Social support' BCT (n = 26) but there was a wide variation in which BCTs were commonly used. it is still unclear to what extent BCTs are accessible for people with a learning disability
	Harris et al. (2015), UK	6 & 0 UK	5/6 studies were high quality and 1 was of moderate quality	Young adults (16-24 years)	6	Physical activity interventions	Body weight and composition	There was no significant effect of physical activity interventions on body weight or body composition outcomes

158

Category	Author, year, location of corresponding author	No. of included studies, No. from the UK	Quality of included studies	Population	No. of RCT included	Type of interventions included	Outcome/s of interest	Summary of main finding/s
	Maïano et al. (2014), Canada	9 & 0 UK	Weak to moderate	7-22-year olds with mild-moderate learning disability	Not clearly reported	Interventions designed to promote changes in body weight and composition e.g. dieting, physical activity, health promotion, and/or cognitive behavioural	Changes in body weight and composition (weight, body mass index, body fat, waist circumference)	Despite the limitations of included studies, intervention outcomes suggest successful changes in weight, body mass index and fat mass
	Jackson et al. (2015), UK	1 & not reported	Unclear risk of bias	People aged 12+ with a learning disability and epilepsy	1	Non- pharmacological. Included but not limited to surgical procedures, diets, psychological, yoga, acupuncture and relaxation therapy	Retention on treatment, freedom from seizures, reduction in seizure frequency and severity. Secondary outcomes included behavioural, cognitive outcomes, adverse effects, and quality of life	As only one study was identified, implications for practice is limited. There is a need for well-designed RCTs to assess the effectiveness of non-pharmacological interventions on seizures and behavioural outcomes.

Summary of interventions reported by systematic reviews and meta analyses								
Category	Author, year, location of corresponding author	No. of included studies, No. from the UK	Quality of included studies	Population	No. of RCT included	Type of interventions included	Outcome/s of interest	Summary of main finding/s
	Spanos et al. (2013), UK	22 & 4 UK	Not clearly reported but appears to be low quality	Adults aged >18	None, Quasi-exp. design	Non-surgical or pharmacological interventions	Impact of intervention on total body weight and/or BMI. Categorised as; 1. Behaviour change 2. Behaviour change plus physical activity 3. Dietary 4. Physical activity 5. Diet plus physical activity 6. Multi component (three or more components)	Current data indicate weight management interventions in those with LD differ from recommended practice and further studies to examine the effectiveness of multi-component weight management interventions for adults with ID and obesity are needed.

	-							
Summary of interventions reported by systematic reviews and meta analyses								
Category	Author, year, location of corresponding author	No. of included studies, No. from the UK	Quality of included studies	Population	No. of RCT included	Type of interventions included	Outcome/s of interest	Summary of main finding/s
	Kerr et al. (2013), UK	9 & 6 UK	Poor to moderate	Adults	1	Tobacco and/or alcohol interventions such as information / advice, education, group support, other psychological / pharmacological interventions	Reduced bio markers for smoking and alcohol use, quality of life, knowledge and attitudes	Identified limited robust evidence and a lack of theoretical framework, but highlighted the importance of issues linked to the appropriateness of interventions (e.g. use of pictures, quizzes, role play, incentives). Highlights the need for large-scale, well designed trials

Summary of interventions reported by systematic reviews and meta analyses								
Category	Author, year, location of corresponding author	No. of included studies, No. from the UK	Quality of included studies	Population	No. of RCT included	Type of interventions included	Outcome/s of interest	Summary of main finding/s
Carer-led	Hithersay et al. (2014), UK	24 & 4 UK	Small scale, with short follow up, studies and varying levels of quality. Efficacy could not be assessed	Adult and child participants older than 2 years	14	Carer-led health interventions; health check questionnaire, health promotion, symptom monitoring & management, mental health & screening	Physical and mental health	The only existing interventions found were carer-completed health diaries which, while being well received, failed to improve health outcomes. Studies in non-learning disability populations show promise, but the paucity of research of engaging carers for people with a learning disability remains unknown

Summary of interventions reported by systematic reviews and meta analyses								
Category	Author, year, location of corresponding author	No. of included studies, No. from the UK	Quality of included studies	Population	No. of RCT included	Type of interventions included	Outcome/s of interest	Summary of main finding/s
Challenging behaviour	Sheehan and Hassiotis (2017), UK	21 & 5 European	Studies lacked in volume, quality and scope	Adults	1 (reported in two studies)	The reduction or discontinuation of antipsychotic medication	Proportion of participants achieving dose reduction or discontinuation without drop out or reinstatement of the antipsychotic. Secondary outcomes included behavioural and health outcomes	Antipsychotics can be reduced or discontinued in a significant proportion of adults, though not always without adverse reactions. There is a group who display behavioural deterioration on antipsychotic reduction that prevents discontinuation; predictors of poor response could not be reliably identified. It was not possible to apply a population level approach due to the relative lack of data and methodological limitations of the available studies

-								
Summary of interventions reported by systematic reviews and meta analyses								
Category	Author, year, location of corresponding author	No. of included studies, No. from the UK	Quality of included studies	Population	No. of RCT included	Type of interventions included	Outcome/s of interest	Summary of main finding/s
	Leong et al. (2015), Australia	17 & not reported	The average total overall quality score was 29.2 out of 65, with a standard deviation (SD) of 9.2, and a range of 16.3–46.0	All age groups and mainly challenging behaviours (11 studies)	0	Sensory integration therapy (SIT)	Sensory integration and perceptual- motor measures; short and long term functional measures	Of the eight studies where SIT was compared to another intervention, the alternative intervention was found to be more effective in all but one study, in which mixed results were reported. In the nine studies where SIT was researched without comparison to an alternative treatment, positive results were reported. There is a need to employ designs that allow for adequate demonstration of experimental control

			Summary of interventions reported by systematic reviews and meta analyses					
Category	Author, year, location of corresponding author	No. of included studies, No. from the UK	Quality of included studies	Population	No. of RCT included	Type of interventions included	Outcome/s of interest	Summary of main finding/s
	Kok et al. (2016), Netherlands	11 (reported in 12 reports) &	Low or unclear risk of bias. Used JHAD scale for inclusion.	Children with mild to borderline learning disability and a psychiatric disorder	11 though not clearly reported	Parent training programmes, social competence training and cognitive behaviour therapy	Challenging behaviour	Parent training programmes reduced challenging behaviour such as conduct problems, disruptive behaviour, hyperactivity and oppositional behaviours (SMD -0.48 95%;CI 0.48—0.12, 1 2 43%). Two studies supported the use of parent training for effectively stimulating development of children with autism symptoms (SMD -0.42 95%;CI 12.61—2.39, I 2 0%). There was some evidence to improve cognitive ability. There was limited evidence to support interventions on social competence training and cognitive behaviour therapy

	Summary of interventions reported by systematic reviews and meta analyses							
Category	Author, year, location of corresponding author	No. of included studies, No. from the UK	Quality of included studies	Population	No. of RCT included	Type of interventions included	Outcome/s of interest	Summary of main finding/s
	Ogg Groenendaal et al. (2014), The Netherlands	20 & not reported	Mostly low quality	All ages with challenging behaviour	Not reported	Physical activity & exercise	Change in challenging behaviour	Significant decrease in challenging behaviour after participating in an exercise intervention (M = 30.9%, 95% CI: 25.0, 36.8). Furthermore, no significant difference was found between high (M = 32.2%) and low (M = 22.9%) intensity exercise interventions. More research is needed to optimize recommendations about the exact intensity, duration, frequency, and mode (group or individual) of exercise interventions

	Summary of interventions reported by systematic reviews and meta analyses							
Category	Author, year, location of corresponding author	No. of included studies, No. from the UK	Quality of included studies	Population	No. of RCT included	Type of interventions included	Outcome/s of interest	Summary of main finding/s
Mental health	Koslowski et al. (2016), Germany	12 (10 in meta-analyses) & not reported	Moderate and high heterogeneity	Adults with mild to moderate learning disability	12	Psychotherapy, biological or system level	Behavioural problems, depressive / anxiety symptoms, quality of life and functioning	No significant effect was found for the predefined outcome domains behavioural problems, depression, anxiety, quality of life and functioning. The effect size for depression (d = 0.49) was moderate but non- significant

								Summary of interventions reported by systematic reviews and meta analyses
Category	Author, year, location of corresponding author	No. of included studies, No. from the UK	Quality of included studies	Population	No. of RCT included	Type of interventions included	Outcome/s of interest	Summary of main finding/s
	Vereenooghe and Langdon (2013), UK	22 & 12 UK	Reported methodological issues	Aged >5 years	0	Psychological principles and techniques	Prevention or treatment of emotional, behavioural or mental health problems	Group-based interventions had a moderate but smaller treatment effect than individual-based interventions. Cognitive behaviour therapy (CBT) was efficacious for both anger and depression. Interventions aimed at improving interpersonal functioning were not effectual. There was limited evidence regarding the efficacy of other psychological therapies and those to treat mental health problems in children and young people. Adults with concurrent mental health problems appear to benefit from psychological therapies

Category	Author, year, location of corresponding author	No. of included studies, No. from the UK	Quality of included studies	Population	No. of RCT included	Type of interventions included	Outcome/s of interest	Summary of main finding/s
Summary of interventions reported by systematic reviews and meta analyses								
Severe or profound learning disability	Houwen et al. (2014), Netherlands	45 (46 articles) & not reports	Not clearly reported	All ages with severe or profound learning disability (i.e. IQ < 35, mental age)		Motor interventions	Improve motor, cognitive, and/or social outcomes	Thirty-eight articles reported improvement in basic motor skills and eight articles reported improvement in recreational or more specialist motor skills. None of the articles reported negative effects due to motor interventions. Further research is required to determine which motor interventions are the most effective in the long-term

			Summary of interventions reported by systematic reviews and meta analyses					
Category	Author, year, location of corresponding author	No. of included studies, No. from the UK	Quality of included studies	Population	No. of RCT included	Type of interventions included	Outcome/s of interest	Summary of main finding/s
Health services	Balogh et al. (2016), Canada	7 & not reported	Assessed risk of bias, which ranged from low to high risk. But most had a low risk of bias despite small sample sizes	Adults	7	Developing and implementing evidence-based guidelines and protocols, supporting guidelines or protocols through health provider, self-management and reorganising health services	Behavioural, mental and physical health problems, and health system use. Secondary outcomes included psychological health and quality of life.	Community-based behaviour therapy might decrease behavioural problems. There are no well-designed studies focusing on organising health services of persons with a learning disability and concurrent physical problems. Few interventions targeted mental health needs, but the results need corroboration

						Summary of interventions reported by systematic reviews and meta analyses		
Category	Author, year, location of corresponding author	No. of included studies, No. from the UK	Quality of included studies	Population	No. of RCT included	Type of interventions included	Outcome/s of interest	Summary of main finding/s
	Robertson et al. (2017), UK	35 & 17 UK	Low	All age groups with a learning disability and epilepsy	0	Interventions aiming to improve knowledge or practice in relation to service responses	Current knowledge or practice in relation to service responses and factors associated with outcomes for people with intellectual disabilities and epilepsy	There are no methodologically robust studies on service-related interventions for people with intellectual disabilities and epilepsy. Further research on improving service delivery is required to substantiate findings associated with access to specialists, the relative efficacy of different models of service provision, use of epilepsy care plans, seizure diaries or risk assessments and awareness

Summary of interventions reported by systematic reviews and meta analyses								
Category	Author, year, location of corresponding author	No. of included studies, No. from the UK	Quality of included studies	Population	No. of RCT included	Type of interventions included	Outcome/s of interest	Summary of main finding/s
Parenting	Wilson et al. (2014), UK	7 & not reported	Low	Adults with mild/moderate learning disability	1	Interventions for parents with learning disabilities	Not restricted by outcome as long as it was quantitatively assessed	Interventions aimed at strengthening social relationships was inconclusive. Despite some limitations, the evidence for parental skills teaching suggested that behavioural based interventions are more effective than less intensive forms such as lesson booklets and the provision of normal services. There is a need for further large scale controlled studies in this area to provide clearer evidence