Learning disability needs assessment

Updated 2017

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Executive Summary

Learning disability is a lifelong condition that affects the way a person learns new things in any area of life. It affects people’s understanding of information and their communication skills. Learning disability is often classified by severity into mild learning disability, moderate or severe learning disabilities. People with learning disability can have difficulty in understanding new or complex information, learning new skills and coping independently. This means that people with a learning disability often suffer many disadvantages and poorer outcomes than their non-disabled peers. This may be due to impairments associated with a learning disability (intellectual, medical and physical), negative attitudes and social exclusion. This may also be due to discrimination and "diagnostic overshadowing". This means that in some cases symptoms of physical ill health are mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person's learning disabilities (Emerson and Baines, 2010).

The 2012 Learning Disability Joint Needs Assessment (LDNA) provided a comprehensive picture of the needs of people with learning disabilities and there has been some progress made in implementing the diverse range of recommendations made. However, based on an assessment of progress on prior recommendations, more could be done towards better collaborative working on developing strategies and the identification of:

- Population subgroups (e.g. older adults or those with profound learning disabilities);
- Those coming into contact with the criminal justice system and incorporating this into the Reducing Reoffending Strategy;
- The impact of specialist services (now requires monitoring against the Health Equality Framework);
- Health action plans (although this should be covered by the health check framework);
- Those accessing dental and eye care services;
- Complaints;
- Parents with learning disabilities;
- There are still gaps concerning children with a learning disability and those transitioning into adult services, however, this should be covered by the 2017 Special Educational Needs and Disability needs assessment.

An update of the LDNA is now required to incorporate new evidence, policy and structural changes. This updated LDNA has assessed the health and social needs of people with learning disabilities across Cornwall and the Isles of Scilly. It is hoped that it will inform current and future service provision to better meet the needs of this population. The aspiration is to build on this needs assessment as new evidence becomes available so that it can be incorporated into the strategic commissioning plans across health and social care. Notably the Shaping Our Future Health and Social
Care Plan for Cornwall and the Isles of Scilly and the Community Based Support and Housing Commissioning strategy and Transforming Care Plan (due to commence during 2019/20).

The areas covered by the needs assessment are:

- National context. This chapter sets the scene across the UK with a description of the prevalence of learning disabilities, along with wider lifestyle and socio-environmental determinants.
- Policy. Places learning disability in the context of recent policy and legislation changes and guidance.
- Cornwall. This builds on the national context by describing the current and future needs of local people with a learning disability.
- Community voice. Description of the views of commissioners, services users and other wider stakeholders.
- Review of effective interventions.
- Recommendations

This LDNA represents the first part of the update. A second update is planned to incorporate findings from additional research to further our understanding of the health needs of people with a learning disability in Cornwall, as well as the experiences, expectations and aspirations of service providers and users.
Scope

Joint strategic needs assessments (JSNAs) are a regular statutory task for Health and Wellbeing board partners to jointly produce information about people with learning disabilities, and to inform future policies and strategies. This is set out by the Local Government and Public Involvement in Health Act 2007 and the Health and Social Care Bill 2011 (PHE, 2016a).

The term ‘learning disabilities’ refers to a significant and disabling general impairment in intellectual and social functioning that is acquired during childhood (Emerson, 2010). This does not include learning disabilities such as dyslexia or people experiencing a brain injury or trauma (Emerson, 2010). Learning disability is used here to describe people with mild, moderate, severe or profound and multiple learning disabilities (NICE, 2016).

Cornwall’s 2012LDNA provides a comprehensive picture of the health and well-being needs of people with learning disabilities across Cornwall and the Isles of Scilly (Brigham and Cohen, 2012). The purpose of this update is to incorporate; 1) changes and progress made since the 2012 needs assessment recommendations; 2) an aspiration from stakeholders to publish a shorter needs assessment; and 3) several changes in policy, legislation, guidance and commissioning. For example, these includes the adaption of the Health and Social Care Act 2012 (amending the Health Act 2007), the Care Act 2014, Section 75 (Partnership arrangements made between NHS bodies and local authorities), learning disability Concordat (response to Winterbourne View) and the Confidential Inquiry into the Deaths of People with Learning Disabilities (CIPOLD).

While this needs assessment update incorporates information on children, it should be read alongside the 2017 SEND (special educational needs and disability) needs assessment, which focuses on children and children transitioning into adulthood. It is recognised that people with a learning disability may also have autism (Department of Health, 2001), but this does not include those with a higher level autistic spectrum disorder who may be of average or even above average intelligence (e.g. Asperger’s Syndrome). This update excludes a specific focus on autism and autistic spectrum disorders (ASD). Please refer to the 2017 autism JSNA focus paper for further information.

The scope of this LDNA update includes an assessment of the; health and well-being of people with a learning disability living in Cornwall and the Isles of Scilly; provision and uptake of services; and identifies recommendations for change. A further update is planned to coincide with the next strategic planning cycle in 2019/20. This will include evidence from quantitative and qualitative research to assess the health, views, needs and aspirations of people with a learning disability. This will help to integrate the experiences and perceptions of people with LD, their carers and service providers into the LDNA process.
The 2017 LDNA has been produced in collaboration with multidisciplinary teams at Cornwall Council (Public Health, Health Promotion, Commissioning, Performance and Improvement), Kernow Clinical Commissioning Group (KCCG) and Cornwall Partnership Foundation Trust (CPFT). This update has been written for service providers and commissioners to help inform future rounds of strategic planning and service provision.
1.0 Introduction

People with learning disabilities are people first, with the right to be treated with dignity and respect. People with a learning disability do not want to be defined solely by their learning disability as they have many other identities, such as friend, neighbour, relative or colleague. Moreover, people with a learning disability have the right to enjoy the same opportunities and responsibilities as other local citizens. This includes access to suitable housing, education and employment, achieving good health outcomes, and leading active and fulfilling lives.

People with learning disabilities often suffer many disadvantages and poorer health outcomes compared to the rest of the population. This can in part be due to intellectual, medical and physical impairments, but it is also due to disabling barriers, discriminatory negative attitudes and social exclusion that also need to be overcome.

The term ‘learning disability’ is useful in identifying some of these barriers, identifying the problems and solutions, and in planning responses. However, there is a need to recognise people also have a gender, age, ethnicity, faith and sexuality and may have other disabilities, impairments or disadvantages that are of equal or greater importance.

Much of what needs to change is within our wider society. There is a need to offer greater and better access to housing, health, education, leisure and employment opportunities, alongside specialised support for those who need it.

There is an increasing national and international body of evidence as to the pattern of needs of people with learning disabilities. In 2012 the first detailed combined assessment of the health and social needs of people with learning disabilities that live in Cornwall was produced by Public Health. This report provides an update and highlights a joint vision to enable everyone with a learning disability and their carers to have greater choice and control to live a fulfilling valued life.

1.1 Aim

The aim of this JSNA is to assess the health and social needs of people with learning disabilities across Cornwall and the Isles of Scilly. To identify gaps in current service provision; make recommendations for changes to meet people’s needs; and reduce the health inequalities experienced by this population group.
1.2 Objectives

The objectives of this JSNA are to assess the:

1. health and well-being status of people with a learning disability living across Cornwall and the Isles of Scilly;
2. gaps/duplication in current service provision;
3. requirements and recommendations for change; and
4. views, needs and aspirations of people living in Cornwall and Isles of Scilly with a learning disability

1.3 Learning disability working group

This update of the needs assessment has been developed in collaboration with the Public Health team and the learning disability needs assessment working group comprising of;

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<th>Working group members</th>
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The scope of the needs assessment has also been shared with Healthwatch, who facilitate the learning disability partnership board (LDPB). The LDPB meet 6 times a year and provides an opportunity for self-advocates and family carers to have their voices heard. Information from these meetings has been included into this needs assessment.
2.0 National Context

2.1 Definition of learning disability

The department of Health defines ‘learning disability’ as having a significantly reduced ability to; understand new or complex information; learn new skills (impaired intelligence); and cope independently (impaired social functioning). This starts before adulthood and has a lasting effect on development (Department of Health, 2001). Children and young people may also have a special educational needs and disabilities (SEND), which is defined more broadly as learning difficulties in the education sector. While used interchangeably with learning disability, this term excludes specific disorders such as reading and writing (dyslexia) or maths (dyscalculia), physical impairments or behavioural difficulties (Department for Work and Pensions, 2016) i.e. those who do not have a significant general impairment in intelligence (Holland, 2011).

Intelligence is a broad concept that includes the ability to reason, comprehend and make judgements. Standardised psychometric tests are used to define someone’s IQ (Intelligence Quotient). Diagnosis cannot be attributed without clear evidence of meeting the 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) or clinical judgement of skilled clinicians can be undertaken (Shankar et al., 2017).

An assessment criteria for children and adults with a learning disability has been previously established (Emerson, 2010). This criteria recognises that people with an IQ ≤70 have a learning disability, with varying levels of severity (Department for Work and Pensions, 2016). However, all professionals agree that IQ should not be used in isolation to assess the degree of learning disability. Unfortunately, they do not consistently use the same categories (Table 201a), which can lead to confusion (Department for Work and Pensions, 2016).
Furthermore, 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 (Shankar et al., 2017). There are no single databases recording individuals with a learning disability and accessing local services, therefore, this update recognises that GP registers captures the largest known administrative population. This is widely accepted as a definition among policy makers and practitioners, and known to capture people accessing social care and specialist services such as those provided by Cornwall Foundation Partnership Trust. For this reason, this needs assessment recognises that the total number of people recorded on GP registers as having a learning disability represents those currently known to services.

### 2.2 Special educational needs, learning difficulties and learning disabilities

In an educational context children are described primarily as having special educational needs (SEN) rather than learning difficulties and disabilities. This falls under the requirements of Special Educational Needs and Disability (SEND) legislation. A child or young person has a SEND if they have a learning difficulty or disability which calls for special educational provision to be made for him or her (Department for Education, 2016). The SEND categories include four categories that are associated with learning disabilities (Emerson and Hatton, 2008b):

- Moderate learning difficulties
- Severe learning difficulties
- Profound and multiple learning difficulties
- Autistic spectrum disorder
2.3 Prevalence of learning disabilities amongst children and adults

The prevalence of people with a learning disability known to GP practices (i.e. the administrative prevalence) in 2014/15 was 0.44% (rate per 1,000 data not reported) for all age groups (PHE, 2016a). Across England during the same period, there were 3.73 per 1,000 adults (18 to 64) with a learning disability getting long term support from Local Authorities. There were 33.7 per 1,000 children with a learning disability being known to schools. This includes 28.6, 3.80 and 1.29 per 1,000 children being known to schools for having moderate, severe, profound and multiple learning disabilities, respectively (PHE, 2016a).

In 2014/15, 70,065 children in England with a primary need associated with learning disabilities had a statement of special educational needs/education health and care plan. Of these, 44% were identified as having moderate learning difficulties (MLD), 41% severe learning difficulties (SLD) and 15% profound and multiple learning difficulties (PMLD). An increasing proportion of children with MLD, SLD and PMLD are being educated in special schools (PHE, 2015a). By adulthood, many with mild learning impairments will have gradually learned and acquired the necessary life skills to live independently, work, marry, raise families, and will not consider themselves to be disabled, and nor will their family, friends and others (Brugha et al., 2012). There is also an abrupt decline in age-specific administrative prevalence of learning disabilities at the point of transition to adult services, illustrating the existence of a “hidden majority” of adults with learning disabilities (Emerson and Glover, 2012).

This may be reflected in the change in true prevalence rates. The true prevalence of learning disabilities (i.e. those known and not known to services) has been estimated to be 2.7% and 2.16% of children and adults (18+ years) have a learning disability, respectively during the same period. However, overall prevalence rates may not be accurate of the true prevalence of learning disabilities because of the ‘hidden majority’ of adults with learning disabilities who typically remain invisible to prevalence type estimates (PHE, 2015a). These include those with a mild learning disability who are not accessing services.

With some exceptions (principally supported accommodation), during 2014/15 social care services were being provided for fewer adults with learning disabilities compared to 2013/14, with accompanying reductions in spending (PHE, 2015a). This has occurred alongside a predicted 1.04% (lower estimate of eligibility, services only provided to new entrants with critical or substantial needs) to 7.94% (upper estimate, services are provided to new entrants with critical, substantial or moderate needs) sustained growth in the need for social care services for adults with learning disabilities up to 2026 (Emerson and Hatton, 2008b). A national perspective of adult social care services can be found from a recent Public Health England report (PHE, 2015a). This provides a national overview of adults receiving adult social care services, types of resident accommodation, those using self-directed support (e.g. personal budgets), some form of community care service (e.g. day services, home
care, professional support and home adaptations) and gross expenditure (e.g. residential care).

### 2.4 Parents with a learning disability

Information on numbers of parents with learning disabilities is not known. It has been estimated that around 1.3% of households with children in England contained a parent with a learning disability. Children of parents with a learning disability were associated with a range of lifestyle and behavioural problems. For example, this included an increased risk of child developmental delay and child speech and language problems (Emerson and Brigham, 2014). Social services and child welfare need access to training and professional development in supporting mothers with learning disability (Strnadová et al., 2017). This is necessary for maintaining the health and wellbeing of their children, especially in areas such as the prenatal period (Guay et al., 2017) and in the provision of adequate care (Lindberg et al., 2017).

### 2.5 Health inequalities

People with learning disabilities are amongst the most socially excluded and vulnerable groups, with greater health needs than the rest of the population (Emerson et al., 2011). There is evidence of poorer health compared to their non-disabled peers as measured by self-rated health, multiple morbidity, arthritis, cancer, diabetes, obesity, measured grip strength, measured lung function and polypharmacy, as well as epilepsy and sensory disabilities (Emerson et al., 2016, Emerson and Baines, 2010). Furthermore, 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 (Emerson et al., 2016). It is important to take a life course approach (i.e. from early childhood to adulthood) because when compared with their non-disabled peers, children with learning disabilities are:

- less likely to have been breastfed at all or breastfed exclusively
- more likely to live in rented housing, overcrowded housing, housing in a poor state of repair and housing that was too cold in winter
- more likely to be exposed to tobacco smoke
- at increased risk of exposure to violence, including bullying, physical, sexual, emotional abuse or neglect
- less likely to have a close relationship with their mother
- more likely to be exposed to inconsistent and harsh parenting and more chaotic family environments
- more likely to be exposed to a greater number and wider range of potentially adverse life events

Compared to people without learning disabilities, people with learning disabilities are more likely to use a wide range of general hospital services, particularly paediatrics, dentistry and psychiatry, with substantial geographical variation (PHE, 2015a).
2.6 Physical and mental health needs

In adulthood, one in seven adults with a learning disability rate their health as not good, which is likely to be an underestimate (Emerson et al., 2011). When compared to the general population, typical health problems experienced by people with a learning disability includes; respiratory diseases and infections, gastro-oesophageal reflex disease and swallowing problems, heart disease, cancer (oesophageal, stomach and gall bladder cancer and leukaemia), gastrointestinal disorders, poor oral health and sensory impairments, metabolic and endocrine disorders (e.g. osteoporosis, thyroid disease and diabetes) and posture/mobility problems. Similarly, adults with learning disabilities are more vulnerable to mental health problems (e.g. caused by biological, psychological, social and family factors) than the general population, and are less likely to get them diagnosed. Rates of dementia are four times higher in those with learning disabilities when compared with the general population, with earlier onset (Brigham and Cohen, 2012).

Of the adults with a learning disability, between 20% and 33% also have autism in England (Emerson and Baines, 2010). The proportion of adults with learning disabilities and autism are estimated to range between 20% and 30%. Similarly, the estimated percentage of children with learning disabilities and autism ranges from 12%-72%, with an average of 34% (Emerson and Baines, 2010). Around 22% of people with a learning disability also have epilepsy, which increases with increasing levels of disability and age (Robertson et al., 2015). Having a learning disability and epilepsy has a pervasive impact on health, quality of life, and thus the psychosocial well-being of people with a learning disability (Kerr et al., 2009, Emerson et al., 2011). This population also has very high rates of challenging behaviours and mental health problems (Kerr et al., 2009), which is thought to affect around 10% to 15% of people. The link between poor health and challenging behaviours is complex (Emerson et al., 2012).

2.7 Life expectancy and mortality

While people with learning disabilities have a shorter life expectancy and increased risk of early death when compared to their non-disabled peers, their life expectancy is increasing, particularly for people with Down’s syndrome (Emerson et al., 2011). There is some evidence suggesting that the life expectancy of those with a mild learning disability is approaching to that of the general population (Emerson et al., 2011). The median age at death of people identifiable as having learning disabilities in death certificates has risen steadily from 54 years in 2008 to 58 years in 2012 (Hatton et al., 2013). This means that men and women die between 13 to 20 years and 20 to 26 years younger than the general population, respectively (PHE, 2015a). The severity of a learning disability also reduces life expectancy (Bittles et al., 2002). Those with a profound learning disability may have >20% expected life lost across all age groups (Patja et al., 2000). This means that people with moderate to severe learning disabilities are three times as likely to die early than the general population,
with mortality being particularly high for young adults, women and people with Down’s Syndrome (Emerson et al., 2011).

The confidential inquiry into premature deaths of people with learning disabilities (CIPOLD) found that 22% of people who died were at ages less than 50 at death, compared with 9% for the general population. Nearly half of the deaths (42%) were judged to be premature, which resulted from common causes such as delays or problems with diagnosis or treatment and problems with identifying needs and providing appropriate care in response to changing needs (PHE, 2015a). The three most common causes of death for people with learning disabilities were;

- circulatory diseases (22.9% of deaths);
- respiratory diseases (17.1%); and
- neoplasms (cancers) (13.1%) (PHE, 2015a).

There are two, possibly preventable common causes of death affecting most groups of people with learning disabilities, which includes

- lung problems caused by solids or liquids going down the wrong way (14% of deaths where a condition associated with learning disabilities was reported);
- epilepsy or convulsions (13%) (Glover and Ayub, 2010).

2.8 Causes and risk factors for learning disabilities

2.8.1 Genetic and biological determinants

The causes of learning disabilities cannot be determined in 40%-80% of cases (Emerson, 2012). The causes can be classified as genetic or non-genetic depending on its aetiology. Genetic causes of learning disability accounts for between 30% and 50% of cases, which includes chromosomal abnormalities (e.g. trisomy 21 syndrome, Down’s syndrome, Edward’s syndrome and Patau’s syndrome), inherited genetic traits (e.g. fragile X syndrome) and single gene disorders (e.g. Prader—Willi syndrome, phenylketonuria (PKU), Fragile X syndrome and Tuberous Sclerosis). The causes of non-genetic learning disability are not fully known. It is thought that non-genetic (i.e. environmental) risk factors are extensive and may result from prenatal, perinatal and neonatal exposures (Huang et al., 2016). Other multifactorial disorders include neural tube defects such as spina bifida, which occur as a result of both genetic and environmental factors.

2.8.2 Environmental risk factors for developing learning disabilities

The timing and extent of exposure to environmental risk factors is important. For example, there are typical risk factors that occur during pregnancy (radiation, environmental tobacco smoke, alcohol, drug use and diseases such as rubella and measles) and during labour and birth (e.g. oxygen deprivation, low birth rate, brain damage and congenital hypothyroidism) (Emerson, 2012). A recent systematic review
identified ten prenatal (advanced maternal age, maternal black race, low maternal education, third or more parity, maternal alcohol use, maternal tobacco use, maternal diabetes, maternal hypertension, maternal epilepsy and maternal asthma), one perinatal (preterm birth) and two neonatal (male sex and low birth weight) risk factors (Huang et al., 2016).

2.9 Wider determinants of health

There are five key determinants of health. These include social determinants of health, health problems associated with specific genetic and biological causes of learning disabilities, communication difficulties and reduced health literacy, high risk health behaviours and barriers to healthcare (Turner and Robinson, 2011). The life experiences of people with learning disabilities on these factors are explained by others (Emerson and Hatton, 2008a).

The following provides an overview of some factors that could be targeted to alleviate health risks (Scott and Havercamp, 2016). However, these are wide ranging and may include a host of environmental adversities such as poverty, poor housing, unemployment, overt discrimination, poor diet, inactivity, obesity or underweight, substance use (e.g. smoking, alcohol, drugs and medication misuse), underuse of health care, sexual health and social disconnectedness / isolation (Emerson and Brigham, 2014, Emerson et al., 2011, Scott and Havercamp, 2016).

2.9.1 Physical activity

On average people with a learning disability have low levels of physical activity (Dairo et al., 2016). This is important to consider because increasing levels of moderate or vigorous physical activity among this population would one of the most effective way of improving the health (Robertson et al., 2000). However, higher rates of obesity may be exacerbated because of conditions such as Prader-Willi Syndrome and use of medications (PHE, 2016b).

Increased inactivity and weight puts people with learning disabilities at greater risk of heart disease, high blood pressure, strokes, diabetes, several types of cancer and mobility difficulties. Understanding potential underlying causes people have for their weight problems, diet and exercise are important for achieving and maintaining a healthy weight (PHE, 2016b). Transportation, financial limitations and a lack of awareness of available options have been identified as key barriers. Other salient barriers included a lack of support from caregivers and authority figures (e.g. teachers, coaches and parents) and lack of clear policies for engaging in regular activity in residential and day service programs (Bodde and Seo, 2009).

2.9.2 Substance use

People with a learning disability that misuse alcohol, drugs or prescribed medications are particularly vulnerable. The number of people estimated to have a problem with alcohol, drugs and prescribed medication is likely to be under estimated because of
the use of self-reported measures. Also, the ‘hidden majority’ of adults with a mild learning disability (i.e. those not known to services) are more likely to misuse alcohol or drugs. While rates of misuse are thought to be lower than the general population, there is an increasing number of people having a learning disability and living more independently in communities. This potentially increases access to alcohol and other drugs. There is a need for appropriate services to support those who misuse substances (PHE, 2017b). An additional concern is the over prescribing of medication such as antipsychotic drugs (i.e. psychotropic medication can include antipsychotics, antidepressants, mood stabilisers, stimulants or anxiolytics) (Regi, 2017 (in print), Glover, 2015).

### 2.9.3 Housing

People with learning disabilities live in a variety of types of accommodation. Housing is an essential element of care packages and can include dispersed housing in the community or supported housing clustered together to form a separate enclave or community. While clustered housing is generally less expensive to deliver, dispersed housing is a more superior solution when considering cost combined with quality of life outcomes (with the exception of village communities for people with less severe learning disabilities) (Mansell and Beadle-Brown, 2009). However, many 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 (Emerson and Hatton, 2008a) and are less likely to be in employment, education and/or training, and experience problems with social deprivation (Emerson and Hatton, 2008a). The emphasis in Valuing People Now is on using person centred planning and the local housing strategy to identify and improve choice of accommodation. According to Public Health England’s learning disability profiles for England (PHE, 2016a) there were;

- 72.9% Supported adults with learning disabilities living in settled accommodation;
- 26.7% supported adults living in unsettled accommodation;
- 5.6% supported adults whose accommodation status is not known to local authorities; and
- 0.14% supported adults whose accommodation status is severely unsatisfactory.

### 2.9.4 Independent living

The Care Act helps to improve people’s independence and wellbeing. It makes it clear 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 (Department of Health, 2016). An indicator of independent living is the provision of support packages. During 2014/15 17.4% of
supported adults (aged 18-64 years) received a direct payment (PHE, 2016a). In May
2015, there were around 387,050 adults with learning disabilities receiving Disability
Living Allowance (DLA), with numbers consistently increasing year on year. For most
people, DLA is gradually being replaced by Personal Independence Payments (PIP),
where the number of people with ‘global learning disabilities’ is small but rapidly
increasing (from 8,233 people in March 2015 to 24,340 people in March 2016).
Attendance allowance is paid to disabled people over the age of 65 to help with
personal care. From 2002 to 2015, the number of people with learning difficulties
claiming Attendance allowance has declined by 2.8% per year to 1,250 people in 2015
(PHE, 2015a).

2.9.5 Education
In 2014, there were 28.6 children per 1,000 pupils with moderate learning difficulties
known to schools in England. Rates for children with a severe or profound and
multiple learning difficulty in England were 3.80 and 1.29 per 1,000 pupils. Nationally,
in 2013-14, 15.0% of adult learners declared learning difficulties and/or disabilities,
which was a higher proportion than in 2012 to 2013 (13.2%) and in 2011 to 2012
(11.8%) (PHE, 2016c). Of the number of all-age apprentices, 8.3% declared learning
difficulties and/or disabilities. This was a higher proportion than in 2012 to 2013
(8.1%) and in 2011 to 2012 (7.8%). It was a lower proportion than in 2010 to 2011
(8.4%). Success rates for those in all-age apprenticeships and adult education and
training ranged from 65.5% to 86.7%, respectively (Skills Funding Agency, 2016a).

2.9.6 Employment
People with learning disabilities value work as a significant part of their lives, and
many want to participate in regular paid employment (Ellenkamp et al., 2016). During
2014/15, 5.9% of supported adults with learning disability were in paid employment
(PHE, 2016a). In comparison 49% of the wider disability community and 79% of the
general population are in work (Mencap, 2016). Recent trends show that the number
of adults with learning disabilities in any paid/self-employment has dropped from
9,905 people in 2011/12 to 7,430 people in 2014/15 (6% employment rate), with
most people (71%) working less than 16 hours per week (PHE, 2015a). Relevant work
environment-related factors for obtaining and maintaining work in competitive
employment include supporting the employers by paying specific attention to:
employers’ decisions, job content, integration and work culture and job coaches
(Ellenkamp et al., 2016).

2.9.7 Transport
Good transport links makes better access to services and activities within
communities and helps to promote active travel (Coronini-Cronberg et al., 2012),
which can reduce the risk of being obese (Webb et al., 2011). People who have a
learning disability, which has a substantial effect on their day to day activities, can
apply for a concessionary bus pass, which must be supported by letters of support.
Those with a permanent disability can be issued with a bus pass for a maximum of 5 years; otherwise passes normally last for 12 months. It is necessary to get medical or social care authorities to confirm whether a person with a disability will qualify, which can take time and incur a fee (e.g. a doctor’s letter).

2.9.8 Relationships
The mental and physical health of people with learning disabilities can be exacerbated by social isolation (Fulford and Cobigo, 2016). Intimate relationships are important and highly valued, despite some evidence of abuse (Bates et al., 2017, Bates et al., 2016). They have been found to promote higher emotional wellbeing in this population who experience higher levels of loneliness (Fulford and Cobigo, 2016).

2.9.9 Access to health care
The health inequalities faced by people with learning disabilities in the UK start early in life, and result, to an extent, from barriers people face in accessing timely, appropriate and effective health care (Emerson et al., 2012). This is evident by the low number of people accessing health promotion, screening (e.g. vision, hearing, dental care, cervical smear tests, breast examination/mammography, bowel and prostate screening) and immunisation (Emerson et al., 2012). Potential barriers includes anxiety, lack of understanding of the test, transportation problems, and the need for extra staff to accompany patients (Wilkinson et al., 2007). In the UK, Emerson et al. (2012) highlight a range of potential barriers, which includes:

- scarcity of appropriate services;
- physical and informational barriers to access;
- unhelpful, inexperienced or discriminatory healthcare staff;
- increasingly stringent eligibility criteria for accessing social care services;
- failure of health care providers to make ‘reasonable adjustments’ in light of the literacy and communication difficulties experienced by many people with learning disabilities; and
- ‘diagnostic overshadowing’ (e.g. symptoms of physical ill health being mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person’s learning disabilities).

People with a learning disability and not known to services are also less likely to access some health services and promotion activities. In addition, people having learning disabilities are more likely to be exposed to some known social determinants of poorer health (greater material hardship, greater neighbourhood deprivation, reduced community, and social participation) (Emerson, 2011).

2.10 Safeguarding, crime, prejudice and discrimination
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 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.

In 2014/15 safeguarding referrals were made for 15,715 people with learning disabilities, with a consistent decrease from 2011/12 to 2014/15 (PHE, 2015a). However, unless attention is given to the additional barriers and issues faced by this group, their sexual exploitation will remain invisible and continue (Franklin, 2015). It is estimated that between 2 and 10% of people with a learning disability are known to offend (Lindsay, 2011) and likely to experience issues in custody, as well as problems associated with understanding anti-social behaviour orders (Brigham and Cohen, 2011). The risk of sex offending and victimisation signals the need for specialised interventions to prevent offending and to ensure victims are assisted with access to justice, support, and treatment (Nixon et al., 2017). Improved education regarding sexuality, empowerment programmes and carer training is required (Wissink et al., 2015). These need to overcome the impact of feeling a lack of control and respect, which require early intervention to avoid problems later in adulthood. For example, improved support and self-control may help reduce the impact of challenging behaviour.

2.10.1 End of life care
People with learning disabilities are often marginalised from mainstream health-care services because of the complexities of a disability. People can be under-referred to specialist palliative care owing to a limited understanding of its role and little collaborative working. There is a need for ongoing staff development focusing on staff confidence, collaborative working between professionals, and the empowerment of people with a learning disability to be involved in decisions about their end-of-life care (Dunkley and Sales, 2014). It is important to put reasonable adjustments into palliative care and end of life care services so that people with learning disabilities have improved end of life care experiences (Giraud-Saunders et al., 2014). ReSPECT is a process that creates personalised recommendations for a person’s clinical care in a future emergency when unable to make or express choices. It provides health and care professionals responding to that emergency with a summary of recommendations to help them to make immediate decisions about that person’s care and treatment. ReSPECT can be complementary to a wider process of advance/anticipatory care planning (ReSPECT, 2017).

2.10.2 Challenging behaviour
Some people with a learning disability and/or autism display behaviour that challenges. Behaviour can be described as challenging when it is of such “intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive
or result in exclusion” (NHS England, 2015b). Rates of challenging behaviour are also higher in people with more severe disabilities and within inpatient settings. In educational, health, and social care settings, prevalence rates of challenging behaviour in people with learning disabilities vary from 10% to 15%, with rates peaking between the ages of 20 and 49 years (Pilling, 2015). Challenging behaviours can form through an inability to satisfy needs and communicate effectively. Therefore, promoting better communication systems will help address some of the difficulties and challenging behaviour of people with learning disabilities (Hutchins, T.L. & Prelock, P.A. 2014). A number of guidelines are available for supporting people with challenging behaviour (NHS England, 2015b, Pilling, 2015), including the Transformation Care Programme.

2.10.3 Carers

The needs of carers should be seen as separate to those of the person with a learning disability. This means that an assessment of carers needs should be undertaken, which should take into consideration of their concerns about the lack of planning for the future (Department of Health, 2001). From 2007/08 to 2014/15, there has been a reduction in the number of family carers of an adult with learning disabilities getting a service for themselves as carers, with the number of family carers getting information / advice / signposting plateauing from 2010/11. Over half (51.4%) of 6,160 surveyed family carers of an adult with learning disabilities (almost all of whom lived with the family carer) spend 100+ hours a week caring for that person. Almost three quarters (74.3%) had been in a caring role for over 20 years and almost a third (30.2%) were not in paid employment due to their caring responsibilities (PHE, 2015a).

It is estimated that 25% of people with a learning disability only become known to services when their carers become too old or too frail to continue to provide care for them (Institute of Public Care, 2009). This means that as people with learning disabilities age, they are likely to experience short to long-term problems with care into older age. While more information is needed in this growing older population, more preventative support is needed to sustain the caring relationship while the family is living together, to support families to plan for the future, and to provide support when the caring relationship breaks down (Walker and Ward, 2013). This is important because parents of aging adults with learning disabilities feel they do not receive sufficient support or receive enough information and practical resources. They continue caring despite poor mental and/or physical health. For this reason, there is an urgent need to review how individuals with learning disabilities and parent carers are supported throughout their lifespan (Cairns et al., 2013).
3.0 Policy Context

Over the past 10 years, there have been several government documents and policies about how health and social care services should be delivered in the future. These policies contain several common themes that are about; supporting people better to enable them to live in the community; providing support and care closer to home; avoiding people going into hospital unnecessarily; and providing alternatives to residential care and other inflexible service models. There has been a fundamental shift to giving people much more choice and control over their lives, which is supported by new flexible ways of working, such as Direct Payments and Personal Budgets, rather than just offering people a limited range of services.

Equality Act 2010 (Directgov, 2013)

From 1 October 2010, the Equality Act replaced most of the Disability Discrimination Act (DDA); however, the Disability Equality Duty continues to apply. Disability under the Equality Act 2010 means you have a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal daily activities.

Disabled people have important rights of access to everyday services, where providers are obliged to make reasonable adjustments to premises and the way they provide services. This includes physical access and about making services easier for everybody to use and that there is more accessible health information for example (Harris et al., 2016).

Valuing People (Department of Health, 2001, Hatton et al., 2005) and Valuing People Now (Department of Health, 2009b)

Despite their year of publication these policies continue to maintain the momentum and value base for services today and have been the real drivers for change in the world of learning disability and commissioning.

The key message and principles they contain are:

“That all people with a learning disability are people first with the right to lead their lives like any others, with the same opportunities and responsibilities, and to be treated with the same dignity and respect. They and their families and carers are entitled to the same aspirations and life chances as other citizens”.

This key message and principles behind “Valuing People” remain the focus and will be relevant for many generations to come. They continue to rightly inform and guide the way services for people with learning disabilities are commissioned and are shaped with the following broad principles:
**Rights**
People with learning disabilities and their families have the same human rights as everyone else.

**Independent living**
This does not mean living alone or having to do everything yourself. All disabled people should have greater choice and control over the support they need to go about their daily lives; greater access to housing, education, employment, leisure and transport opportunities and to participation in family and community life.

**Control**
This is about being involved and in control of decisions made about your life. This is not usually doing exactly what you want, but is about having information and support to understand the different options and their implications and consequences, so people can make informed decisions about their own lives.

**Inclusion**
This means being able to participate in all the aspects of community – to work, learn, get about, meet people, be part of social networks and access goods and services – and to have the support to do so.

**Valuing Employment Now (Department of Health, 2009a)**
Valuing Employment Now set out the goal to radically improve employment opportunities for people with learning disabilities in England, and particularly for people with moderate and severe learning disabilities.

If real disability equality is to be achieved, work needs no longer to be seen as optional for people with moderate and severe learning disabilities. The default position must be that everyone will have the chance to get a job. There should be choice about what work people do, just as for non-disabled people.

People with profound and complex disabilities should not be excluded from the world of work. International evidence shows that it is possible for people with severe disabilities to make an important economic contribution to society.

**The Care Act 2014 (Legislation.gov.uk, 2014)**
The Act aims to create a single, modern law that makes it clear what kind of care and support people with a learning disability and their carers should expect and to receive care and support through the principle route of a personal budget. The key focus of the act is the statutory principle of individual wellbeing and aims to achieve; clearer and fairer care and support; physical, mental and emotional wellbeing of both the individual needing care and their carer; preventing, reducing and delaying the need
for care and support; and putting people in control of their own care (Harris et al., 2016).

A summary of key changes includes:

- A minimum eligibility threshold across the country – a set of criteria that makes it clear when local authorities will have to provide support to people;
- Local authority duty to consider the physical, mental and emotional wellbeing of the individual needing care. They will also have a new duty to provide preventative services to maintain people’s health;
- The care system to be built around each person through Personal Budgets;
- A cap on personal ‘care costs’ (not including accommodation costs) of £72,000;
- Carers to be entitled to an assessment and services in their own right;
- Ensure no one goes without care if providers fail, regardless of who pays; and
- Transition from children to adults right to assessment before age 18.

The Act places a requirement and duty on all Local Authorities to; collaborate and integrate with other public authorities (e.g. housing, health); to ensure that information, advice and independent advocacy is available to all when they need it; to provide people with a choice of diverse and high quality care providers and ensure no vulnerable person is left without the care they need; and outlines a new statutory safeguarding framework (Harris et al., 2016).

**The Autism Act 2009 (NAS, 2017)**

The Autism Act 2009 was the first ever disability-specific law in England. It placed a duty on the Government to produce a strategy for autistic adults (published in March 2010), and a duty on the Government to produce statutory guidance for local councils and local health bodies on implementing the adult autism strategy by the end of 2010 (published in December 2010). The adult autism strategy is the Government’s plan to make sure that autistic adults get the help that they need. It explains the different things that the Government will do to make sure autistic adults get the help that they need. The strategy also tells local councils and health services how they can help autistic people. The first ever strategy for autistic people in England – entitled Fulfilling and rewarding lives – was published in 2010 with a commitment to review this strategy three years later. In 2013, the Government asked for feedback from autistic adults, parents, carers and professionals about how well the 2010 strategy had been implemented so far. The new strategy, Think Autism, was published in April 2014.


From 1st August 2016 onwards, all organisations that provide NHS care and / or publicly-funded adult social care are legally required to follow the Accessible Information Standard. The Standard sets out a specific, consistent approach to
identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.

**Personalisation**

In recent years there have been many publications relating to local authority and health service reform.

A fundamental re-think of the relationship between citizens and public services runs through for example:

- Improving the Life Chances of Disabled People
- Our Health, Our Care, Our Say
- Putting People First
- Vision for Adult Social Care- Capable Communities and Active Citizens 2010
- Think Local, Act Personal 2011- Sector wide commitment to moving forward with Personalisation and community based support and
- ‘Caring for our future: reforming care and support’ White Paper

The main messages are very clear.

- To provide a personalised approach, where citizens are empowered to have more say and control in all aspects of public life and participate as active and equal citizens.
- Have maximum control of their own lives, including control of their own health and social care needs
- Are supported to live independently, stay healthy and recover quickly.
- Have choice and control so that any support they may need fits the way they wish to live their lives.

**Mansell report (Department of Health, 2007b)**

Good practice guidance on the delivery of services for people with learning disabilities and challenging behaviour or mental health needs. It places a requirement for commissioners to better use investment in the development and expansion of the capacity of local services, and the provision of specialist services for people with the most challenging needs. The report emphasises:

1. the responsibility of commissioners to ensure that services meet the needs of individuals, their families and carers;
2. a focus on personalisation and prevention in social care;
3. that commissioners should ensure services can deliver a high level of support and care to people with complex needs/challenging behaviour; and
4. that services/support should be provided locally where possible.
There is also a broad range of policy and guidance which influences the direction of current and future service delivery.

**Transforming Care (Department of Health, 2012b, Department of Health, 2012a, NHS, 2015b)**

In response to the abuse of people at Winterbourne View hospital, Valuing People sets out a programme of action to transform services. This aims to ensure that people no longer live inappropriately in hospitals. It ensures that people are cared for in line with best practice, based on their individual needs, and that their wishes and those of their families are listened to and are at the heart of planning and delivering their care. It requires a reduction in reliance on inpatient care and a fundamental change across many organisations to deliver transforming care requirements, along with examples of best practice being carried out across the country (Department of Health, 2012b).

A Concordat (Department of Health, 2012a) was published alongside this report. This sets out a shared commitment to transform services, and specific actions to make real change in the care and support for people with learning disabilities or autism with mental health conditions or behaviour that challenges. The Concordat promised: “health and care commissioners will review all current hospital placements and support everyone inappropriately placed in hospital to move to community-based support as quickly as possible and no later than 1 June 2014”. It envisaged a “rapid reduction in hospital placements for this group of people”, and “the closure of large-scale inpatient services” (Transforming Care and Commissioning Steering Group, 2014).

There has been some progress since these reports, however, much more needs to be done. The next steps report highlights the commitment to transforming care for people with learning disabilities and/or autism who have a mental illness or whose behaviour challenges services (NHS, 2015b). The report sets out five key areas to develop including empowering individuals, the right care in the right place, workforce development, regulation and inspection, and data.

Published alongside these next steps, the “Building the Right Support” (NHS England, 2015a) sets out a national plan to be delivered by the end of 2018. It sets out a simple vision that people with learning disability and/or autism have the right to the same opportunities as anyone else to live satisfying valued lives and to be treated with dignity and respect. They should have a home, be able to develop and maintain relationships, and get the support they need to live healthy, safe and fulfilling lives in the community. The service model (NHS England, 2015b) sets out further nine core principles, actions for health and social care commissioners, along with relevant guidance and standards. Local commissioning strategies should cover quality of life, keeping people safe, choice and control, support and interventions and equitable outcomes for people with learning disabilities.
The National Service Model (NHS England, 2015b)

1. People should be supported to have a **good and meaningful everyday life** - through access to activities and services such as early years services, education, employment, social and sports/leisure; and support to develop and maintain good relationships.

2. Care and support should be **person-centred, planned, proactive and coordinated** – with early intervention and preventative support based on sophisticated risk stratification of the local population, person-centred care and support plans, and local care and support navigators/keyworkers to coordinate services set out in the care and support plan.

3. People should have **choice and control** over how their health and care needs are met – with information about; care and support in formats people can understand; the expansion of personal budgets; personal health budgets and integrated personal budgets; and strong independent advocacy.

4. People with a learning disability and/or autism should be supported to live in the community with **support from and for their families/carers as well as paid support and care staff** – with training made available for families/carers, support and respite for families/carers, alternative short term accommodation for people to use briefly in a time of crisis, and paid care and support staff trained and experienced in supporting people who display behaviour that challenges.

5. People should have a choice about where and with whom they live – with a choice of **housing** including small-scale supported living, and the offer of settled accommodation.

6. People should get good care and support from **mainstream NHS services**, using NICE guidelines and quality standards – with Annual Health Checks for all those over the age of 14, along with Health Action Plans, Hospital Passports where appropriate, liaison workers in universal services to help them meet the needs of patients with a learning disability and/or autism, and schemes to ensure universal services are meeting the needs of people with a learning disability and/or autism (such as quality checker schemes and use of the Green Light Toolkit).

7. People with a learning disability and/or autism should be able to access **specialist health and social care support in the community** – via integrated specialist multi-disciplinary health and social care teams, with that support available on an intensive 24/7 basis when necessary.

8. When necessary, people should be able to get **support to stay out of trouble** – with reasonable adjustments made to; universal services aimed at reducing or preventing anti-social or ‘offending’ behaviour; liaison and diversion schemes in the
criminal justice system; and a community forensic health; and care function to support people who may pose a risk to others in the community.

9. When necessary, when their health needs cannot be met in the community, they should be able to access high-quality assessment and treatment in a hospital setting, staying no longer than they need to, with pre-admission checks to ensure hospital care is the right solution and discharge planning starting from the point of admission or before.

**Winterbourne View (Transforming Care and Commissioning Steering Group, 2014)**

The pledge made in the Governments Concordat (Department of Health, 2012a) was missed (Transforming Care and Commissioning Steering Group, 2014). The pledges made are still valid and require community-based support to safely discharge people currently in inpatient settings; and support people in the community to prevent admissions in the first place. This led to a number of recommendations for a national commissioning framework under which local commissioners would secure community-based support for people with learning disabilities and/or autism. These includes strengthening rights, forcing the pace of commissioning, closure of inpatient institutions, building capacity in the community and holding people to account (Transforming Care and Commissioning Steering Group, 2014).

**Other legislation in relation to children, young people and families with learning disabilities**

- SEND Code of Practice January 2015
- Children and Families Act 2014
- Children and Families Bill 2013
- The Breaks for Cares of Disabled Children regulations 2011
- Children Act 2004
- Education Act 2001
- Special Educational Needs and Disability Act 2001

**National reports and guidance**

**Next steps on the NHS 5 year forward view (NHS, 2017)**

Highlights progress made. A range of commitments have been made, including the co-production of national improvement strategies, new fact track ‘Nurse First’ programme initially targeting mental health and learning disability nursing, continued action on inappropriate hospitalisation of people with learning disabilities, expanded employment programme and learning from deaths.

**The Health Equality Framework (HEF) (NDTi, 2013)**
The Health Equality Framework (HEF) is an outcomes tool based on the determinants of health inequalities and is designed to help commissioners, providers, people with learning disabilities and their families understand the impact and effectiveness of services.

The HEF is endorsed by the National Valuing Families Forum and professional senate. It is referenced in NHS England and Department of Health reports. It is also referenced in the Joint Self-Assessment Framework, can be implemented across health and social care, and can support local authorities with their duty to promote wellbeing under the Care Act 2014.

Fulfilling and rewarding lives (Department of Health, 2011)

This 2010 strategy provides a clear framework for all mainstream services across the public sector to work together for adults with autism. 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; and
- a clear, consistent pathway for diagnosis.

Autism is a lifelong developmental disability and although some people can live relatively independently, others will have high dependency needs requiring a lifetime of specialist care. There are approximately 400,000 adults with Autistic spectrum disorders in England, around half of whom have a learning disability.

‘Treat me right’ (Mencap, 2004) and ‘Death by Indifference’ (Mencap, 2007)

The 2004, Mencap report ‘Treat me right’ (Mencap, 2004) exposed the unequal healthcare that people with learning disabilities often received. It concluded that although some of the reasons were known why people with learning disabilities died young, an inquiry into the premature deaths of people with learning disabilities should be conducted. In 2007, following the deaths of six people with learning difficulties receiving NHS care, Mencap published their report ‘Death by Indifference’ (Mencap, 2007). It highlighted the institutional discrimination within healthcare services towards people with learning disabilities, their families and carers and criticised the lack of response at Government level to the Disability Rights Commission. Factors contributing to institutional discrimination include;

- people with a learning disability are seen to be a low priority;
- many healthcare professionals do not understand much about learning disability;
• many healthcare professionals do not properly consult and involve the families and carers of people with a learning disability;
• many healthcare professionals do not understand the law around capacity and consent to treatment;
• health professionals rely inappropriately on their estimates of a person’s quality of life; and
• the complaints system within NHS services is often ineffectual, time-consuming and inaccessible.

The report called for; an independent enquiry into the six cases identified in the report; confirmation that the confidential inquiry into the premature deaths of people with a learning disability will take place; major improvements to the investigation of complaints against the healthcare system.

The Confidential Inquiry into the deaths of people with learning disabilities (Heslop et al., 2013)

Following the institutional discrimination identified by Mencap (2007), a Confidential Inquiry into the deaths of people with learning disabilities (CIPOLD) was undertaken to investigate avoidable or premature deaths through a series of retrospective reviews of deaths (Heslop et al., 2013). This Confidential Inquiry into the deaths of people with learning disabilities took place from 2010 to 2013 and reviewed the deaths of 247 people with learning disabilities, approximately 2.5 times the number expected. The median age of death for people with learning disabilities (65 years for men; 63 years for women) was significantly less than for the UK population of 78 years for men and 83 years for women. Thus men with learning disabilities died, on average, 13 years sooner than men in the general population, and women with learning disabilities died 20 years sooner than women in the general population. Overall, 22% were under the age of 50 when they died.

Using the same definition as is used in the child death review process, 43% of the deaths of people with learning disabilities were unexpected. Of the 238 deaths of people with learning disabilities for which agreement was reached by the Overview Panel, 42% were assessed as being premature. The most common reasons for deaths being assessed as premature were; delays or problems with diagnosis or treatment; and problems with identifying needs and providing appropriate care in response to changing needs.

As with the general population, the most common underlying causes of death were heart and circulatory disorders (22%) and cancer (20%), although both were less prevalent than in the general population (29% and 30% respectively). The final event leading to death was most frequently a respiratory infection in the people with learning disabilities. Few (23%) death certificates mentioned that the cause was having a learning disability. Of note is that the CIPOLD Overview Panel identified some additional deaths that they thought should have been reported to the coroner, and expressed concerns about some coroners’ reviews of deaths.
People with learning disabilities had a considerable burden of ill-health at the time of their death. Key issues that appeared to be problematic were the lack of coordination of care across and between the different disease pathways and service providers, and the episodic nature of care provision. In addition, the review found a lack of understanding of the mental capacity act among health and social care professionals, deficiencies in record keeping, inappropriate orders not to resuscitate and poorly coordinated end of life care.

The review recommended the following low-cost and effective measures:

- improved communication within and between agencies;
- a named health professional to coordinate care for individuals with multiple health conditions;
- use of patient or carer-held health records;
- proactive use of annual health checks in order to plan based on changing needs;
- the identification of advocates to help people with learning disabilities to access healthcare services; and
- further recommendations related to the understanding among professionals of the mental capacity act, the appropriate use of orders not to resuscitate and the routine collection of data on the mortality of people with learning disabilities.

**Healthcare for all (Department of Health, 2008)**

The Mencap’s report, *Death by indifference* (published in March 2007), led to the setting up of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities by Sir Jonathan Michael, which was commissioned by the then Secretary of State for Health (Department of Health, 2008). Healthcare for All, published in July 2008, found significant gaps between the law, policy and the delivery of effective services for people with learning disabilities. Ten recommendations were made to strengthen the systems for assuring the quality of health services at all levels. Following the publication of *Death by indifference*, Mencap, on behalf of the six families involved, asked the Health Service and Local Government Ombudsmen to investigate complaints about all six cases (Local Government Ombudsman, 2009).

**Six lives (Local Government Ombudsman, 2009)**

The Department of Health published a progress report in 2009 on ‘six lives’, following the 2007 Mencap report, *Death by Indifference*.

The Six Lives report (Local Government Ombudsman, 2009) outlined case studies of six people with learning disabilities who Mencap believed died unnecessarily as a result of receiving lower standards of care. The investigation reports illustrate some significant and distressing failures in service across both health and social care, leading to situations in which people with learning disabilities experienced prolonged suffering and inappropriate care. One of the recommendations required all NHS and
social care organisations to urgently review the effectiveness of systems in place to
meet the needs of people with learning disabilities, and the capacity and capability of
service delivery (Local Government Ombudsman, 2009).

While some things have improved, for example, an increased number of health checks
and people telling us that reasonable adjustments are making a difference to their
lives, this report shows that more needs to be done. Service providers need to work
together to change the culture and strengthen the leadership across the health and
social care system to support better healthcare outcomes for people with learning
disabilities, their families and carers (Department of Health, 2013).

**A Vision for Adult Social Care: Capable Communities and Active Citizens**
*(Department of Health, 2010)*

In 2010 the Care Services Minister launched ‘A vision for adult social care: Capable
communities and active citizens’ (Department of Health, 2010). The Vision for a
modern system of social care is built on seven principles:

- **Personalisation**: individuals not institutions take control of care. Personal
  budgets, preferably as direct payments, are provided to all eligible people.
  Information about care and support is available for all, regardless of whether or
  not they fund their own care.
- **Partnership**: care and support delivered in a partnership between individuals,
  communities, the voluntary and private sectors, the NHS and councils –
  including wider support services, such as housing.
- **Plurality**: the variety of people’s needs is matched by diverse service provision,
  with a broad market of high quality service providers.
- **Protection**: there are sensible safeguards against the risk of abuse or neglect.
  Risk is no longer an excuse to limit people’s freedom.
- **Productivity**: greater local accountability will drive improvements and
  innovation to deliver higher productivity and high quality care and support
  services. A focus on publishing information about agreed quality outcomes will
  support transparency and accountability.
- **People**: it is possible to draw on a workforce who can provide care and support
  with skill, compassion and imagination, and who are given the freedom and
  support to do so.

These key principles are important in that they are helping to drive changes in service
delivery, examples of which are highlighted in the innovation and good practice case
studies. They also echo and reinforce the principles of good practice set out in the
Mansell guidance.

**No voice unheard, no right ignored** *(Department of Health, 2015b)*

A consultation to explore views on a range of proposals that are intended to
strengthen or build upon existing policies for people with learning disabilities, autisms
and mental health conditions (Department of Health, 2015b). In response to the
consultation, there is a need for further action to realise the vision of everyone being treated with dignity and respect by health and care services and enjoying the same rights as everyone else. The proposed actions are clustered into three implementation phases, including early actions that seek to sustain momentum generated, legislative changes and more radical solutions to longer-term issues, as well as ongoing monitoring and review (Department of Health, 2015a).

**Local Transformation Plan 2016-2019.**

The purpose of this local Transforming Care Plan (TCP) is to set out intentions to transform services for people of all ages with a learning disability and/or autism in Cornwall and the Isles of Scilly who display behaviour that challenges, including those with a mental health condition (in line with Building the Right Support). Cornwall Council, the Council of the Isles of Scilly and NHS Kernow Clinical Commissioning Group (NHS Kernow) have formed a transforming care partnership to develop and implement the local plan. This presents an opportunity to improve integration between health and social care in Cornwall and the Isles of Scilly, to continue to make improvements in patient care and significantly reshape services where needed.

**Learning Disabilities Mortality Review (LeDeR) Programme**

This national and local programme aims to make improvements to the lives of people with learning disabilities; clarifying any potential modifiable factors associated with a person’s death, and preventing them from being repeated. A key part of the LeDeR Programme is to support local areas to review the deaths of people with learning disabilities and make improvements in the provision of services, which is being led by Kernow Clinical Commissioning Group. A further part of the LeDeR programme is to conduct a series of additional projects. These are:

- Finding out more about the age and cause of death of people with learning disabilities in England by linking different data sets.
- Finding out more about the provision of ‘reasonable adjustments’ for people with learning disabilities.
- Providing better guidance so that the cause of death written on death certificates of people with learning disabilities is recorded in a consistent manner.
- Establishing a collection of reports about people with learning disabilities from which we can learn more about commonly occurring problems.

**Blood tests for people with learning disabilities: making reasonable adjustments (PHE, 2017)**

This guidance is to help health professionals who need to take blood from someone with a learning disability. It may also be of use to paid social care or health staff and family members when they are supporting someone to have a blood test.
Under the Equalities Act 2010, public sector organisations have to make changes in their approach to ensure that services are accessible to disabled people as well as everybody else. This report is the 14th in a series of reports looking at reasonable adjustments in a specific service area, which includes making reasonable adjustments during blood tests. The aim of these reports is to share information, ideas and good practice in relation to the provision of reasonable adjustments.

**NICE**

A range of NICE guidance documents are available for the delivery of services for people with learning disabilities who have mental health problems and challenging behaviours;

Mental health problems in people with learning disabilities: prevention, assessment and management: guidance (NG54) provides recommendations on;

- organising and delivering care;
- involving people in their care;
- prevention, including social, physical environment and occupational interventions;
- annual GP health checks;
- assessment;
- psychological interventions, and how to adapt these for people with learning disabilities; and
- prescribing, monitoring and reviewing pharmacological interventions.

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges: guidance (NG11) provides recommendations on;

- general principles of care;
- support and interventions for family members or carers;
- early identification of the emergence of behaviour that challenges;
- assessment;
- psychological and environmental interventions;
- medication; and
- interventions for coexisting health problems and sleep problems.

**Other guidance documents**

- Good practice guidance on commissioning specialist adult learning disability health services (Department of Health, 2007a).
- Commissioning guidance for Clinical Commissioning Groups (IHAL, 2012).
- Health inequalities & people with learning disabilities in the UK: Implications and actions for commissioners (Turner and Robinson, 2011). Highlights the
need to; publish a Joint Strategic Needs Assessment on learning disability (the focus of this paper); work across partner agencies to address wider determinants of health (e.g. poverty and housing); improve annual health checks and access to healthcare; raise awareness of healthy lifestyles; and measure progress.

- Working together 2 (PHE, 2014b) is an update of the Working together guide published in 2008 to help hospital staff, family members and paid support staff work jointly before, during and towards the end of any hospital admission (unplanned or planned) so an individual with learning disabilities could get good support and treatment.

- Annual health checks for people with learning disabilities - step by step toolkit for people with learning disabilities. The toolkit collects guidance and resources to help GPs, practice nurses and the primary administration team organise and perform quality Annual Health Checks on people with a learning disability.

4.0 What’s happening in Cornwall and the Isles of Scilly

Cornwall and the Isles of Scilly is the second largest local authority area in the South West region, covering an area of 3,559 sq. km, and has the longest coastline of all English counties at 697 km. It is an area of many contrasts; with varied landscapes including remote rural, costal and environmentally sensitive areas, interspersed with villages and historic market towns; where affluence sits alongside some of the most disadvantaged areas in England. In line with national trends, Cornwall has a growing and aging population (Figure 5.1), although this is not consistent across all areas of Cornwall. Typical challenges include areas of deprivation and associated health inequalities, high demand for affordable housing, transport infrastructure and the economy. However, Cornwall is a relatively safe place, and its environmental assets are extremely valuable to the economy and quality of life (Cornwall Council, 2016).
Figure 4.0a Population of Cornwall in 2015 and 2030 estimated projections
4.1 Need

Learning disability is an extremely stigmatising condition and involves the utilisation of public health resources. However, there is no definitive record of the number of people with learning disabilities (Hatton et al., 2013). It is difficult to be exact with prevalence of learning disability both nationally and locally because there are a range of complex factors that underlie the predictions in numbers of people. The most authoritative and widely used research and baseline evidence is provided by PANSI & POPPI data (Emerson and Hatton, 2008b), which is the best currently available (Institute of Public Care, 2017a, Institute of Public Care, 2017b). This methodology allows us to estimate future demand, but is limited to adults aged 18 years and above. To provide a more comprehensive picture, the following also provides the latest known administrative prevalence of learning disabilities across all age groups (i.e. those registered with GP practices) and estimated administrative and true (i.e. administrative prevalence plus those not potentially not known to services) prevalence projections.

4.1.1 Estimated numbers with a learning disability in Cornwall using national prevalence figures

According to the Projecting Adult Needs and Information System (PANSI & POPPI), 10,482 adults in Cornwall had a learning disability in 2017. By 2035 this figure is expected to increase to 18,785 (Table 4.1.1a). Many people with a mild to moderate learning disability live their lives without recourse to services, either living independently or with help from family and friends. In contrast, adults with a moderate to severe learning disability are more likely to be in receipt of services. The 2017 estimate for adults with a moderate or severe learning disability is 2,122 and the 2035 estimate is 2,301 (Table 4.1.1b). There is also expected to be a slight increase in the number of adults aged between 18 and 64 years with a severe learning disability, which rises from 453 in 2017 to 475 adults in 2035 (Table 4.1.1c).

<table>
<thead>
<tr>
<th>People by age</th>
<th>2017</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
<th>2035</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>1,176</td>
<td>1,140</td>
<td>1,119</td>
<td>1,247</td>
<td>1,280</td>
</tr>
<tr>
<td>25-34</td>
<td>1,399</td>
<td>1,454</td>
<td>1,496</td>
<td>1,437</td>
<td>1,479</td>
</tr>
<tr>
<td>35-44</td>
<td>1,468</td>
<td>1,473</td>
<td>1,549</td>
<td>1,631</td>
<td>1,661</td>
</tr>
<tr>
<td>45-54</td>
<td>1,843</td>
<td>1,770</td>
<td>1,609</td>
<td>1,582</td>
<td>1,674</td>
</tr>
<tr>
<td>55-64</td>
<td>1,734</td>
<td>1,837</td>
<td>1,949</td>
<td>1,881</td>
<td>1,720</td>
</tr>
<tr>
<td>65-74</td>
<td>1,682</td>
<td>1,690</td>
<td>1,633</td>
<td>1,790</td>
<td>1,915</td>
</tr>
<tr>
<td>75-84</td>
<td>839</td>
<td>962</td>
<td>1,224</td>
<td>1,282</td>
<td>1,289</td>
</tr>
<tr>
<td>85 and over</td>
<td>341</td>
<td>368</td>
<td>442</td>
<td>572</td>
<td>7767</td>
</tr>
<tr>
<td>Total</td>
<td>10,482</td>
<td>10,694</td>
<td>11,021</td>
<td>11,422</td>
<td>18,785</td>
</tr>
</tbody>
</table>
Table 4.1.1b People predicted to have a moderate/severe learning disability, likely to be in receipt of services

<table>
<thead>
<tr>
<th>People by age</th>
<th>2017</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
<th>2035</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>273</td>
<td>265</td>
<td>264</td>
<td>297</td>
<td>306</td>
</tr>
<tr>
<td>25-34</td>
<td>301</td>
<td>312</td>
<td>322</td>
<td>309</td>
<td>318</td>
</tr>
<tr>
<td>35-44</td>
<td>369</td>
<td>370</td>
<td>390</td>
<td>411</td>
<td>419</td>
</tr>
<tr>
<td>45-54</td>
<td>413</td>
<td>396</td>
<td>362</td>
<td>360</td>
<td>382</td>
</tr>
<tr>
<td>55-64</td>
<td>376</td>
<td>398</td>
<td>420</td>
<td>402</td>
<td>367</td>
</tr>
<tr>
<td>65-74</td>
<td>271</td>
<td>271</td>
<td>264</td>
<td>290</td>
<td>309</td>
</tr>
<tr>
<td>75-84</td>
<td>87</td>
<td>100</td>
<td>127</td>
<td>130</td>
<td>131</td>
</tr>
<tr>
<td>85 and over</td>
<td>32</td>
<td>34</td>
<td>41</td>
<td>52</td>
<td>69</td>
</tr>
<tr>
<td>Total</td>
<td>2,122</td>
<td>2,146</td>
<td>2,190</td>
<td>2,251</td>
<td>2,301</td>
</tr>
</tbody>
</table>

Table 4.1.1c People predicted to have a severe learning disability

<table>
<thead>
<tr>
<th>People by age</th>
<th>2017</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
<th>2035</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>90</td>
<td>88</td>
<td>87</td>
<td>98</td>
<td>101</td>
</tr>
<tr>
<td>25-34</td>
<td>84</td>
<td>87</td>
<td>90</td>
<td>86</td>
<td>89</td>
</tr>
<tr>
<td>35-44</td>
<td>100</td>
<td>100</td>
<td>105</td>
<td>111</td>
<td>113</td>
</tr>
<tr>
<td>45-54</td>
<td>91</td>
<td>87</td>
<td>80</td>
<td>80</td>
<td>84</td>
</tr>
<tr>
<td>55-64</td>
<td>88</td>
<td>94</td>
<td>99</td>
<td>96</td>
<td>88</td>
</tr>
<tr>
<td>Total</td>
<td>453</td>
<td>456</td>
<td>461</td>
<td>471</td>
<td>475</td>
</tr>
</tbody>
</table>

The number of adults in Cornwall with Down’s syndrome is predicted to remain fairly stable through to 2035 (Table 4.1.1d).

Table 4.1.1d. People predicted to have Down’s syndrome

<table>
<thead>
<tr>
<th>People by age</th>
<th>2017</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
<th>2035</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>27</td>
<td>26</td>
<td>26</td>
<td>29</td>
<td>30</td>
</tr>
<tr>
<td>25-34</td>
<td>35</td>
<td>37</td>
<td>38</td>
<td>36</td>
<td>37</td>
</tr>
<tr>
<td>35-44</td>
<td>37</td>
<td>37</td>
<td>39</td>
<td>41</td>
<td>42</td>
</tr>
<tr>
<td>45-54</td>
<td>49</td>
<td>47</td>
<td>43</td>
<td>42</td>
<td>44</td>
</tr>
<tr>
<td>55-64</td>
<td>48</td>
<td>51</td>
<td>54</td>
<td>52</td>
<td>47</td>
</tr>
<tr>
<td>65 and over</td>
<td>5</td>
<td>5</td>
<td>6</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>201</td>
<td>203</td>
<td>206</td>
<td>206</td>
<td>207</td>
</tr>
</tbody>
</table>
4.1.2 Adults with a moderate or severe learning disability living with a parent

According to national estimates there are 607 adults with a moderate or severe learning disability, aged 18-64 years, living with a parent in Cornwall. The estimated number of people living with a parent falls with age, with a majority being under 44 years old.

<table>
<thead>
<tr>
<th>People by age</th>
<th>2017</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
<th>2035</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>181</td>
<td>175</td>
<td>176</td>
<td>197</td>
<td>203</td>
</tr>
<tr>
<td>25-34</td>
<td>155</td>
<td>161</td>
<td>165</td>
<td>159</td>
<td>164</td>
</tr>
<tr>
<td>35-44</td>
<td>144</td>
<td>144</td>
<td>152</td>
<td>160</td>
<td>163</td>
</tr>
<tr>
<td>45-54</td>
<td>94</td>
<td>89</td>
<td>81</td>
<td>82</td>
<td>87</td>
</tr>
<tr>
<td>55-64</td>
<td>34</td>
<td>36</td>
<td>37</td>
<td>35</td>
<td>32</td>
</tr>
<tr>
<td>Total 18-64</td>
<td>607</td>
<td>606</td>
<td>612</td>
<td>633</td>
<td>648</td>
</tr>
</tbody>
</table>

4.1.3 Challenging behaviour & autism

The number of people predicted to display challenging behaviour is thought to remain stable between 2017 (142 people) to 2035 (144 people) (Table 4.1.3a). The number of people with a challenging behaviour may rise as a result of projected increases in the number of adults with autism. Projections (Table 4.13b) suggest that the number of adults on the autistic spectrum will increase from 4,067 in 2017 to 4,948 by 2035. These estimates do not provide data on the number of adults with a learning disability and autism.

<table>
<thead>
<tr>
<th>People by age</th>
<th>2017</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
<th>2035</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>20</td>
<td>19</td>
<td>19</td>
<td>21</td>
<td>22</td>
</tr>
<tr>
<td>25-34</td>
<td>25</td>
<td>26</td>
<td>27</td>
<td>26</td>
<td>27</td>
</tr>
<tr>
<td>35-44</td>
<td>27</td>
<td>27</td>
<td>28</td>
<td>30</td>
<td>30</td>
</tr>
<tr>
<td>45-54</td>
<td>35</td>
<td>34</td>
<td>31</td>
<td>30</td>
<td>32</td>
</tr>
<tr>
<td>55-64</td>
<td>34</td>
<td>36</td>
<td>39</td>
<td>37</td>
<td>34</td>
</tr>
<tr>
<td>Total 18-64</td>
<td>142</td>
<td>142</td>
<td>143</td>
<td>144</td>
<td>144</td>
</tr>
</tbody>
</table>
Table 4.1.3b. People predicted to have autistic spectrum disorders, by age and gender, projected to 2030

<table>
<thead>
<tr>
<th>Persons by age</th>
<th>2017</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
<th>2035</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>446</td>
<td>432</td>
<td>426</td>
<td>475</td>
<td>491</td>
</tr>
<tr>
<td>25-34</td>
<td>560</td>
<td>589</td>
<td>610</td>
<td>587</td>
<td>605</td>
</tr>
<tr>
<td>35-44</td>
<td>279</td>
<td>577</td>
<td>609</td>
<td>645</td>
<td>661</td>
</tr>
<tr>
<td>45-54</td>
<td>757</td>
<td>720</td>
<td>653</td>
<td>641</td>
<td>675</td>
</tr>
<tr>
<td>55-64</td>
<td>740</td>
<td>784</td>
<td>826</td>
<td>790</td>
<td>723</td>
</tr>
<tr>
<td>65-74</td>
<td>753</td>
<td>753</td>
<td>730</td>
<td>804</td>
<td>851</td>
</tr>
<tr>
<td>75 and over</td>
<td>532</td>
<td>607</td>
<td>768</td>
<td>855</td>
<td>942</td>
</tr>
<tr>
<td>Total population</td>
<td>4,067</td>
<td>4,462</td>
<td>4,622</td>
<td>4,797</td>
<td>4,948</td>
</tr>
</tbody>
</table>

4.1.4 Known administrative prevalence (all ages)

Public Health England report data on the number of people with a learning disability (all age groups) accessing GP services. Although the figures can vary substantially between areas, in part reflecting the geographic distribution of residential care settings (PHE, 2016c). In 2014/15, the administrative (i.e. those registered with a GP) prevalence of learning disabilities across Cornwall was 0.52% (95%;CI 0.50-0.54), which was higher than across England and one of the highest rates in the South West region. In contrast, the Isles of Scilly, had one of the lowest prevalence rates, although the confidence intervals are wide due to the low numbers of people with a learning disability (Figure 4.1.4a).

Figure 4.1.4a  Percentage of people with learning disabilities registered with a GP in 2014/15 (all ages) (PHE, 2016c)
Compared to national data, in 2014 Cornwall had a lower number of children with a learning disability (30.2 per 1,000 people) and those with a moderate learning disability (25.6 per 1,000) known to schools. However, in 2014, Cornwall had a higher number of children with severe learning disabilities known to schools (4.58 per 1,000) than across England (3.80 per 1,000) (PHE, 2016c). Compared to trends across England in 2014/15, Cornwall had a lower number of adults (aged 18 to 64 years) with a learning disability and getting long term support from the local authority (3.02 per 1,000). Recent data from the Quality Outcomes Framework, shows that the number of people with learning disabilities varies substantially across the county (Figure 4.1.4b). Information from the learning disability teams highlight the potential for the prevalence data to be skewed towards the placement of care. For example, there is a campus style residential provision near Launceston (Bowden Derra Park), which is home to around 70 people with learning disabilities with ranging needs. People with a learning disability in this area can access the Carnewater GP practice in Bodmin. This is the only large, campus style facility in Cornwall, who also takes a number of people from out of county (about a 1/6th of their clients).

Figure 4.1.4b  Prevalence / numbers of adults registered on GP practices across Cornwall

The Quality and Outcomes Framework (QOF) is a voluntary programme for all GP surgeries in England. The QOF awards GP practices achievement points for, among other things, managing some of the most common Long Term Conditions such as diabetes and asthma. Learning Disability is one of the conditions where a register is maintained and the map below shows the QOF Practice prevalence rate for those with a learning disability; simply the total number of patients on the register, expressed as a proportion or percentage of the total number of patients registered with the practice.
4.1.5 Estimated administrative and true prevalence using local projections

To gain a better picture of the age profile of people with a learning disability and future projections, learning disability projections across Cornwall have been completed. These have been estimated using small area population and housing based projections (Cornwall Council, 2017g), along with learning disability projection methods from POPPI & PANSI (Emerson, 2004). While this provides a useful small area breakdown, there are some limitations of this approach. The projections are influenced by variations in housing growth (i.e. those not accounted for in these projections), the location of care homes such as Launceston and homes with dedicated placements. Due to the age categories, these estimates are not directly comparable to the national estimates for Cornwall (presented above). However, these small area estimates represent our best available projections for Cornwall. The estimations show that for all ages in 2015, the administrative (i.e. those known to services) and estimated true prevalence (i.e. those known to services and estimated number of people with a learning disability not accessing services) of learning disabilities is 0.43% (2,363 people) and 1.97% (10,785 people), respectively. Consistent with previous projections, forecasts show a slight increase in the number of people with a learning disability by 2030 (Figure 4.1.5a).
In Cornwall, the estimated administrative and true prevalence of learning disabilities across all ages is predicted to continue to rise by 8.6% and 10.5% by 2030, respectively. This means there will be a total of 2,566 people accessing services and 11,920 people with learning disabilities by 2030. The number of people with a learning disability varies by age and gender, with there being a greater number of men than women have learning disabilities (Figure 4.1.5b). The demographic profile shows that there is a higher proportion of people aged between 15-24 years and in older adults (between 40-55 years). By 2030, there is an additional increase in children predicted to have a learning disability. This demonstrates the need for continued timely diagnosis and structured, appropriate support through childhood, effective management of future transition out of children’s education and health services, and adult social services. Future services will need to develop enablement, skills development and support independence building for individuals with learning disabilities. Most notable increasing trend is in older adults aged over 80 years, which suggests a greater need for supported living / extra care housing and support, and palliative care.
Both the estimated administrative and true prevalence of learning disability for children and adults varies considerably across Cornwall (Figure 4.1.5c&d). Higher prevalence rates can be seen around the larger areas such as Camborne, Redruth, Falmouth, St. Austell, Newquay and Truro reflecting the size of these urban areas, and potentially historic changes in the delivery of services such as the transition from institutionalised to community settings.
4.2 Health status for children and adults using the 2014/15 Census on people with learning disabilities

The 2014/15 census (referred to as ‘the census’ throughout) provides information about the health and care of people with learning disabilities (NHS Digital, 2017) and enables comparisons to be made between national and local data. The census provides data on the number of patients recorded on general practices’ (GPs’) learning disabilities registers across Cornwall.

However, limitations exist and caution should be taken when interpreting these results. This was a cross sectional study with variable response rates. This means that it can only provide a single snap shot in time and includes 50.74% and 61.37% GP registered patients across England and Cornwall, respectively. In this survey, there were 1,581 patients on the GP learning disability register compared to the 2,876 patients registered with learning disabilities in Cornwall (NHS Digital, 2016e). This means nothing is known about 1,295 people with learning disabilities who were registered with GP practices but not participating in this survey.

4.2.1 Mortality data from the learning disability census (NHS Digital, 2017)

Evidence from the census data shows that around a third of people with learning disabilities died during the census year when aged over 65 years (Table 4.2.1a). The majority of which were aged over 75 years, further supporting a trend towards increased life expectancy and an aging population.
### Figure 4.2.1a Number of patients ending their registration by death during the year following the Reference Year Start Date where the patient had a recording of a learning disability (NHS Digital, 2017)

<table>
<thead>
<tr>
<th>Age band</th>
<th>Female</th>
<th>Male</th>
<th>Male &amp; female</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of patients</td>
<td>Female %</td>
<td>Number of patients</td>
</tr>
<tr>
<td>0 TO 9</td>
<td>0</td>
<td>0.00</td>
<td>0</td>
</tr>
<tr>
<td>10 TO 17</td>
<td>0</td>
<td>0.00</td>
<td>1</td>
</tr>
<tr>
<td>18 TO 24</td>
<td>0</td>
<td>0.00</td>
<td>0</td>
</tr>
<tr>
<td>25 TO 34</td>
<td>1</td>
<td>0.71</td>
<td>1</td>
</tr>
<tr>
<td>35 TO 44</td>
<td>0</td>
<td>0.00</td>
<td>1</td>
</tr>
<tr>
<td>45 TO 49</td>
<td>0</td>
<td>0.00</td>
<td>1</td>
</tr>
<tr>
<td>50 TO 54</td>
<td>2</td>
<td>3.45</td>
<td>1</td>
</tr>
<tr>
<td>55 TO 59</td>
<td>1</td>
<td>1.85</td>
<td>1</td>
</tr>
<tr>
<td>60 TO 64</td>
<td>1</td>
<td>2.04</td>
<td>2</td>
</tr>
<tr>
<td>65 TO 69</td>
<td>1</td>
<td>3.23</td>
<td>2</td>
</tr>
<tr>
<td>70 TO 74</td>
<td>2</td>
<td>12.50</td>
<td>2</td>
</tr>
<tr>
<td>75 AND OVER</td>
<td>4</td>
<td>19.05</td>
<td>4</td>
</tr>
<tr>
<td>All ages</td>
<td>12</td>
<td>1.63</td>
<td>16</td>
</tr>
</tbody>
</table>

### 4.2.2 Health & disease prevalence data from the learning disability census (NHS Digital, 2017)

The census provides data on patients with a diagnosis of a given disease, as at the Reference Year End Date (Table 4.2.2a). Recorded prevalence rates of gastric oesophageal reflux disease (GORD) were similar between men and women, but differed by age with the highest prevalence occurring between 10 and 17 years and generally in the over 55 year olds. The number of people with a diagnosis of dysphagia in Cornwall is broadly similar to England, which shows that diagnosis rates are similar between men and women across all age groups. A similar trend is found in Cornwall, except for women aged between 65 to 74 years where 10.64% had a positive diagnosis. In contrast, Cornwall has nearly double the number of people diagnosed or being treated for chronic constipation when compared to England. Women appear to be more affected than men with around 10.64% being affected during childhood (0 to 9 years) and late adulthood (65 to 74 years).
Compared to England, Cornwall has a slightly lower number of people with a learning disability and Down’s syndrome, which is similar across men and women. Dementia in this population appears to affect people between the ages of 45 to 54 (1.63%) and 55 to 64 (2.12%). Onset appears to occur earlier in men (ages 35 to 44, 0.74%) and into the 65 to 74 year olds (3.28%). The diagnosis of Hypothyroidism is similar in England and Cornwall, influencing predominantly men and women aged over 25, although 25% of children aged between 0 and 9 years was recorded.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Prevalence of diagnosis, % all age groups</th>
<th>England</th>
<th>Cornwall</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Control</td>
<td>LD</td>
</tr>
<tr>
<td>Gastric oesophageal reflux disease (GORD)</td>
<td></td>
<td>NA</td>
<td>6.84</td>
</tr>
<tr>
<td>Dysphagia</td>
<td></td>
<td>NA</td>
<td>2.57</td>
</tr>
<tr>
<td>Chronic constipation</td>
<td></td>
<td>NA</td>
<td>1.59</td>
</tr>
<tr>
<td>Down’s Syndrome</td>
<td></td>
<td>NA</td>
<td>9.41</td>
</tr>
<tr>
<td>Down’s Syndrome and a diagnosis of dementia</td>
<td></td>
<td>NA</td>
<td>0.66</td>
</tr>
<tr>
<td>Down’s Syndrome and a diagnosis of Hypothyroidism</td>
<td></td>
<td>NA</td>
<td>3.33</td>
</tr>
<tr>
<td>Asthma</td>
<td></td>
<td>5.39</td>
<td>8.83</td>
</tr>
<tr>
<td>Cancer, excluding non–melanotic skin cancer</td>
<td></td>
<td>1.78</td>
<td>0.85</td>
</tr>
<tr>
<td>Chronic kidney disease</td>
<td></td>
<td>3.23</td>
<td>2.72</td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disorder (COPD)</td>
<td></td>
<td>1.81</td>
<td>0.98</td>
</tr>
<tr>
<td>Chronic heart disease (CHD)</td>
<td></td>
<td>3.20</td>
<td>1.12</td>
</tr>
<tr>
<td>Dementia</td>
<td></td>
<td>0.74</td>
<td>1.38</td>
</tr>
<tr>
<td>Depression</td>
<td></td>
<td>11.54</td>
<td>12.23</td>
</tr>
<tr>
<td>Epilepsy with drug treatment</td>
<td></td>
<td>0.60</td>
<td>18.06</td>
</tr>
<tr>
<td>Epilepsy with drug treatment and record of seizure in last 12 months</td>
<td></td>
<td>19.63</td>
<td>27.86</td>
</tr>
<tr>
<td>Epilepsy with drug treatment and seizure free in last 12 months</td>
<td></td>
<td>61.81</td>
<td>45.33</td>
</tr>
<tr>
<td>Heart failure</td>
<td></td>
<td>0.83</td>
<td>0.85</td>
</tr>
<tr>
<td>Hypertension</td>
<td></td>
<td>13.74</td>
<td>9.60</td>
</tr>
<tr>
<td>Severe mental illness</td>
<td></td>
<td>0.87</td>
<td>7.75</td>
</tr>
<tr>
<td>Stroke or transient ischaemic attack</td>
<td></td>
<td>1.72</td>
<td>1.65</td>
</tr>
</tbody>
</table>
The number of people with a learning disability and asthma was slightly higher when compared to the general population (i.e. the control group) across England and Cornwall. In Cornwall, the number of women and men with asthma in the population was mixed with no clear trends with age. Whereas the number of cancer diagnoses appeared to be slightly lower, with slight differences between women and men in Cornwall. Women between the ages of 35 and 64 appeared to be affected (0.68%), whereas men aged above 18 had a cancer diagnosis (1.12%).

Having a chronic kidney disease diagnosis was lower in people with learning disabilities, which appeared to affect women and men from the ages of 18 (3.81%) and 35 (2.89%), respectively. A similar trend was observed in those with a learning disability and COPD and CHD, which generally affected adults, aged over 45 years. Heart failure was identified in adults aged over 18 with slightly higher rates in those aged over 55 years with a learning disability in Cornwall. The number of people diagnosed with hypertension were less than those recorded in the control group, which increased from the age of 35 years, particularly in the over 55 and 75 year olds. There appeared to be more women (10.08%) than men (7.17%) with a hypertension diagnosis. Having a stroke or TIA diagnosis in people with a learning disability in Cornwall appeared to be greater in those aged above 25, particularly in adults aged between 55 to 65 (3.81%), 65 to 74 (4.63%) and over 75 (23.81%).

Dementia was slightly higher in people with learning disabilities, and the diagnosis of dementia in people with learning disabilities appeared to increase earlier in England (age 18 and above) than in Cornwall (age 35 above). Severe mental illness affected more people with a learning disability when compared to the control group, although the difference appeared to be less in Cornwall. Here severe mental illness was diagnosed in adults aged 18 and above, particularly in the over 45 year olds.

In contrast to rates of severe mental illness, rates of depression were slightly lower (10.62%) than the control group (12.94%). This could indicate that there may be a higher proportion with people with a learning disability undiagnosed, with a possible impact on their ability to function independently in the community. Depression
appeared to be slightly higher in women (11.99%) than men (9.68%), which affected children and adults. A higher number of people with a learning disability had a diagnosis and treatment for epilepsy. In Cornwall, there appeared to be a greater number of women (22.48%) than men (17.23%), particularly in children aged between 0 and 9 years (40%). Around 25% of people with a learning disability and epilepsy had a seizure over the last 12 months, with nearly 60% being seizure free, which appeared higher than the average across England.

A higher number of people with a learning disability had a Hyperthyroidism diagnosis. There appeared to be a higher number of women diagnosed with Hyperthyroidism, particularly in those aged over 35. Majority of those with a learning disability and an active diagnosis of diabetes mellitus had a record of IFCC-HbA1c in the last 12 months (i.e. test for diabetes mellitus). Of the patients in Cornwall, 77.67% had an IFCC-HbA1c of 75 mmol/mol or less (satisfactory).

Non-Type 1 diabetes mellitus affected 6.27% and 5.40% of women and men, respectively with a learning disability in Cornwall. Prevalence also appeared to increase with age. Higher prevalence rates were across age bands 45 to 54 (7.49%), 55 to 64 (15.25%), 65 to 74 (15.74%) and over 75 years (21.43%). Diagnosis of Type 1 diabetes mellitus affected 0.44% of people with a learning disability, which was similar across women and men, but diagnosis varied by age. This is probably due to a limited sample size when compared to the age-specific prevalence rates across England.

4.2.3 Body mass index (BMI) data from the learning disability census (NHS Digital, 2017)

The census collected data on the most recent BMI assessment classification (or Down’s Syndrome BMI centile classification), in the 15 months to Reference Year End Date and compared them to the patient control group.

Around a third of people with learning disabilities (28.55%) fall in the healthy weight for BMI (18.5 to 24.9), which is similar to the average across England. There is a higher proportion of people falling in the underweight category (10.77%) of BMI <18.4, which is higher than average rates across England (5.83%). In comparison, 4.40% of the patient control group were classified as being under weight. Being underweight was more common in those aged less than 34 years, although the number of people being underweight declined with age until older age, where more women than men aged over 75 years (12.50% compared to 6.25% in men) were underweight.

A high proportion of people are considered as overweight (BMI 25-29.9) and obese (BMI >30) across all ages (30.38% and 38.12%, respectively), although this is comparable to rates across the patient control group (35.27% and 30.39%, respectively) and people with learning disabilities across England (27.98% and 37.22%, respectively). Across Cornwall, there were more women (47.69%) than men.
who were considered as being obese, particularly in those aged between 35 and 64 years.

4.3 Prescriptions / medication

A pilot study is underway to investigate and reduce antipsychotic drug prescription, which aims to systematically stratify (into low to high risk with those on 2 antipsychotics) and reduce the level of antipsychotic prescribing. A total of 243 patients with a learning disability and registered on a prescription database (known as Eclipse), but no other recorded mental illness and registered with a GP in Cornwall have been included. To ensure the best possibility of success, a STOMP-ID toolkit has been designed to provide assurance for the management of medication (Regi, 2017 (in print)).

A recent research project entitled “learning disability & behaviour: medication use in a community MDT” investigated the prescribing of psychotropic medications to people with learning disabilities and challenging behaviour. The research sought to see how often medication is given to people instead of other health care such as communication or occupational assessments for example. Of the 106 people accessing care relating to challenging behaviours, around 50% get medication to manage their feelings and many do not get other assessments. The study highlights the need to stop over medicating people with learning disabilities and challenging behaviour.

‘The Purple Book’ has also been produced to help people with learning disabilities to look after their own physical health when taking anti-psychotic and / or anti-epileptic medicine.

4.4 Wider determinants of health

There is national evidence on the role of wider determinants of health and the inequalities faced by people with learning disabilities. This includes areas such as housing, poverty, employment and risky lifestyle behaviours such as physical inactivity, taking drugs, smoking and alcohol misuse. Targeting these factors can provide an opportunity to alleviate health inequalities, however, we know little about impact of these wider determinants of health at the local level. Further research with service users, families, carers and health care professionals is required to understand the extent of health inequalities experienced across Cornwall, as well as barriers and facilitators for accessing health services. This will enable the development more targeted strategies in the future, particularly in the commissioning of services and health promotion programmes.

The following provides an overview of housing, education, employment and transport.

4.4.1 Housing, accommodation and support

Adequate housing is essential for people’s health and wellbeing across the life course, particularly for people with learning disabilities. The provision of appropriate
accommodation and care is important to consider because of the projected increase in housing demand. This is predicted to result from increased prevalence of learning disabilities and demographic changes (e.g. local variations in the number of people with learning disability and number of people reaching older age), as well as, the severity of learning disability and those displaying challenging behaviour.

Until now, people have had to apply for several separate benefits because of a low income or did not having an income. The government is now introducing a new benefit called Universal Credit, which means that people will only have to apply for this one benefit instead of the following benefits:

- Income Support
- Income based Jobseekers Allowance (JSA)
- Income related Employment and Support Allowance (ESA)
- Housing Benefit
- Tax Credits

Under Universal Credit, people will have one monthly payment to cover their housing and living costs (Mencap, 2017). This means that people with learning disabilities will need a bank account to claim Universal Credit. This was raised as a risk factor during the Learning Disability Partnership Board (LDPB) meeting on the 19th April 2017, particularly with respect to a lack of support and difficulty in applying for bank accounts.

Transforming adult social care aims to deliver community based support services that set high expectations around helping working age adults into some form of paid employment or purposeful activity and to live in a home of their own (Dowsing and Warrener, 2017). The strategic direction is to increase the range of independent housing options for adults with eligible social care needs, and reduce the number of Supported Living Shared Housing and residential care home placements. This will include support to adapt existing homes, development of new accessible housing, the development of self-contained accommodation with access to health and social care services (Long Term Care Commissioning Team, 2016b). The numbers of people accessing community and housing services and future need is provided by the recent adult and social care ‘Transforming Adult Social Care’ strategy (Table 4.4.1a & b). While it is not clear how many people with a learning disability are accessing these services, the majority of people with a learning disability accessing day care services will have an assessed social care need (i.e. there are few unassessed self-funders).
Table 4.4.1a Estimated community support and accommodation need (Dowsing and Warrener, 2017, Long Term Care Commissioning Team, 2016b, Long Term Care Commissioning Team, 2016a)

<table>
<thead>
<tr>
<th>Community care and support</th>
<th>Number of eligible people accessing a service / units</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supported Living Services</td>
<td>170</td>
<td>The majority of people accessing SLS are people with learning disabilities/physical disabilities and/or autism.</td>
</tr>
<tr>
<td>Long Term Supported Accommodation</td>
<td>90</td>
<td>Support needs related to mental health, learning disabilities and/or autism and may or may not have eligible social care needs.</td>
</tr>
<tr>
<td>Extra Care Housing Schemes</td>
<td>119</td>
<td>For people over 55 years old with age related support needs</td>
</tr>
<tr>
<td>Adult Placement/Shared Lives</td>
<td>140</td>
<td>The majority of people accessing Shared Lives are people with learning disabilities</td>
</tr>
<tr>
<td>Day Activities</td>
<td>700</td>
<td>Number of people with a learning disability is unknown</td>
</tr>
<tr>
<td>Short Breaks</td>
<td>260</td>
<td></td>
</tr>
</tbody>
</table>

Table 4.4.1b Locations of people with learning disabilities and/or autism accessing residential care and supported living services (Dowsing and Warrener, 2017, Long Term Care Commissioning Team, 2016b, Long Term Care Commissioning Team, 2016a)

<table>
<thead>
<tr>
<th></th>
<th>Residential Care - Adult Years</th>
<th>Residential Care - Older Adults</th>
<th>Accessing supported living services and living in rented properties</th>
</tr>
</thead>
<tbody>
<tr>
<td>North Cornwall</td>
<td>75</td>
<td>15</td>
<td>20</td>
</tr>
<tr>
<td>Kerrier</td>
<td>65</td>
<td>15</td>
<td>35</td>
</tr>
<tr>
<td>Caradon</td>
<td>50</td>
<td>10</td>
<td>25</td>
</tr>
<tr>
<td>Penwith</td>
<td>35</td>
<td>10</td>
<td>30</td>
</tr>
<tr>
<td>Restormal</td>
<td>55</td>
<td>15</td>
<td>30</td>
</tr>
<tr>
<td>Carrick</td>
<td>50</td>
<td>5</td>
<td>30</td>
</tr>
<tr>
<td>Total</td>
<td>330</td>
<td>70</td>
<td>170</td>
</tr>
</tbody>
</table>

While these estimates provide a snap shot of housing need, the actual housing and accommodation needs of those with a learning disability accessing and not accessing these services remains unknown. This is important to consider because the number of
people with learning disability accessing supported housing and accommodation is likely to increase in line with the projected population demographic changes.

Public Health England monitors area profiles for accommodation, however, there is no data available for the proportion of people living in settled accommodation, unsettled accommodation in Cornwall (PHE, 2016c). The number of people living in shared ownership homes, social housing, privately rented properties, owner occupied homes or living with a family also remains unknown. Moreover, we do not know the full extent of their living conditions or quality of housing.

4.4.2 Education

The percentage of primary school pupils with a statement of special educational needs and a learning disability is similar across England and Cornwall for those with a moderate learning disability. However, there appears to be a higher proportion of pupils with a severe learning disability, which is a trend seen in secondary schools (Table 4.4.2a).

<table>
<thead>
<tr>
<th>Table 4.4.2a</th>
<th>Number and percentage of pupils with a statement of special education needs and learning disability (Government Statistics, 2016)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Specific Learning Difficulty</td>
</tr>
<tr>
<td></td>
<td>Number</td>
</tr>
<tr>
<td>State-funded primary schools: Number and percentage of pupils with statements of special educational needs (SEN) or at school action plus by type of need, by local authority area and region, England, January 2014</td>
<td></td>
</tr>
<tr>
<td>ENGLAND</td>
<td>29,835</td>
</tr>
<tr>
<td>Cornwall</td>
<td>173</td>
</tr>
<tr>
<td>Isles of Scilly</td>
<td>.</td>
</tr>
<tr>
<td>State-funded secondary schools: Number and percentage of pupils with statements of special educational needs (SEN) or at school action plus by type of need, by local authority area and region, England, January 2014</td>
<td></td>
</tr>
<tr>
<td>ENGLAND</td>
<td>56,190</td>
</tr>
<tr>
<td>Cornwall</td>
<td>427</td>
</tr>
<tr>
<td>Isles of Scilly</td>
<td>.</td>
</tr>
<tr>
<td>Cornwall</td>
<td>424</td>
</tr>
<tr>
<td>Isles of Scilly</td>
<td>.</td>
</tr>
</tbody>
</table>
Special schools: Number and percentage of pupils with statements of special educational needs (SEN) or at school action plus by type of need, by local authority area and region, England, January 2014

<table>
<thead>
<tr>
<th>Year</th>
<th>ENGLAND</th>
<th>Cornwall</th>
<th>Isles of Scilly</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014</td>
<td>36,565</td>
<td>20.3</td>
<td></td>
</tr>
<tr>
<td>2015</td>
<td>77,965</td>
<td>24.9</td>
<td>0.1</td>
</tr>
<tr>
<td>2016</td>
<td>86,992</td>
<td>25.2</td>
<td>0.1</td>
</tr>
</tbody>
</table>

The number of people accessing further education and skills based training is available from the Skills Funding Agency for the years 2010-11, 2011-12 and 2012-13 (Skills Funding Agency, 2016b). The number of people with a learning disability and accessing further education and skills based training for the above years in Cornwall were 6,740, 6,850 and 5,770, respectively. However, little is known about the experiences of people accessing education and training.

4.4.3 Employment

During this period, the south west of England had a greater gap in the employment rate between those with a learning disability and the overall employment rate (70.3%) when compared to England (66.9%), which was greatest among men (73.8%) than women (67.2%) (PHE, 2016c). Public Health England monitors the proportion of people with a learning disability and in employment, however, there was no data recorded in 2014/15 for Cornwall (PHE, 2016c). Cornwall Council has a small supported employment team known as Employability Cornwall. The team supports people with a learning disability and/ or autism to prepare for, find and retain paid employment. However, no data was available at the time of this needs assessment.
4.4.4 Transport

Around 15,000 bus passes have been issued to people with a learning disability since the inception of the Concessionary Fares Scheme in 2010 across Cornwall. Of the 2,496 concessionary bus passes issued over the last 12 months, 376 were for people with learning disabilities. In 2015/16, there were 122,674 journeys made by people with a learning disability and holding a Concessionary Fare Bus Pass, which fluctuates over time.

At the Learning Disability Partnership Board meeting, 19th April 2017, several issues were raised concerning bus passes. Issues raised included the 5-year renewal period for a life-long condition, availability of buses during winter months, lack of provision to use passes before 9.30am, accessibility of online application easy read forms, improved bus stop signage and easy read time tables. The process for obtaining free passes is changing with an aim for all applications to be handled separately using post or online systems. Additional facilities at One Stop shops are being investigated to help with the process.

4.4.5 Healthy behaviours

While there is a need to improve advice for vulnerable groups such as those with a learning disability (e.g. Cornwall’s alcohol 2016–19 strategy), little is known about the extent of healthy behaviours among people having a learning disability in Cornwall. This includes levels of smoking, alcohol, substance misuse, obesity, physical activity and diet.

4.5 Safeguarding, crime, prejudice and discrimination

4.5.1 Safeguarding

Between 1 April 2015 to 31 March 2016 Cornwall (437 per 1,000) and the Isles of Scilly (361 per 1,000) had a lower number of referrals made under the Mental Capacity Act 2005, Deprivation of Liberty Safeguards (DoLS) when compared to England (454 per 1,000) (NHS Digital, 2016c). However, these data do not clearly identify the proportion of referrals that involve people with a learning disability. Furthermore, these data are not available locally because records are not broken down by mental disorder. According to Public Health England during 2014/15, Cornwall had a higher number of referrals of people with learning disabilities (88.8% 95%;CI 78.2-100.4) for adult safeguarding (per 1,000 people on the GP Learning Disability register) when compared to the South West (66.7% 95%;CI 63.6-69.9) and England (62.2% 95%;CI 61.2-63.2) (PHE, 2016c).

Due to the complexity of co-morbidities, which affects 62% of children for example, and recording of primary cause of safeguarding issues, it is difficult to distinguish actual numbers and causes of safeguarding reports among children with a learning disability. Further investigating the safeguarding referrals made by the acute liaison nurse (ALN) service, Cornwall Partnership Foundation Trust and Cornwall Council may...
help identify the number of cases, location, age profile and relationship with perpetrators etc.

Equality, diversity and safeguarding training are provided by these organisations. For example a 126 people have accessed the Learning Disability Awareness e-learning at Cornwall Council since its release in 2016. In terms of mandatory training within the Council, around 3,600 are compliant in terms of carrying out the mandatory equality and diversity training. Cornwall Councils new employee induction pack also includes the ‘Safe Places’ leaflet and face-to-face sessions, which was produced by Health Promotion Service to sign post new employees.

4.5.2 Cornwall’s Criminal Justice Liaison and Diversion Service (CJLDS)

The Community Forensic Mental Health Team offers comprehensive and county-wide community Forensic Mental Health and Learning Care Disability services across Cornwall. This comprises of consultation, assessment, case management, and specialist intervention services. This is available for adults with mental health and/or learning disability needs, and those who have either committed serious offences or whose risk assessment indicates the need for intensive assessment or intervention to manage or reduce the risk of harm to others. The team is made up of specialist forensic psychiatric, psychology and nursing team members (including specialist learning disability nurse) and approved mental health professional & social worker.

The general referral criteria requires an individual to be registered with a GP in the Cornwall area and have mental health or learning disability needs, with evidence, either from previous offending or risk assessment, of a risk of harm to others. There is generally a requirement for the individual to be open at the time of referral to either Community (CMHT) or Inpatient Mental Health Services, although additional cases are taken on occasionally in exceptional circumstances. The service is open to adults above the age of 18 and to those approaching transition from Child and Adolescent services. Further information is available and provides advice on referrers to the liaison clinics, pathway and the local service. These contain summary information regarding all areas of the service.

During 2016/17 there were 948 adult presentations to the Cornwall Liaison and Diversion Service. Of these, 10 people, including 1 woman and 9 men, were identified as having a learning disability need (1.05%). Half of those in contact with the service had previously been in contact with learning disability services, three were on the existing case load and two other had no contact with local services. During this period, no children presented with a suspected Learning disability in custody. Five of the adults with learning disabilities and in contact with CJLDS had an identified social and communication difficulty. Of the ten accessing the service, 6 were bailed, 3 were remanded in custody and one was release with no further action.
4.5.3 Suicide audit group
Public Health coordinates a suicide surveillance group (SSG) that monitors and reviews suicides in Cornwall. Currently, this does not include any record on whether a person had a learning disability. It is possible that this data may be included as part of the LeDeR programme previously described and/or future revisions to the SSG database.

4.6 Parents with a learning disability
There is still a need to better understand; the number of parents with a learning disability; the number of children with parents who have a learning disability; the number of children in care with a parent with a learning disability; and the number of child carers with a parent who has a learning disability. There is also a lack of information about the numbers of parents in contact with services and whether these families’ needs are being addressed. This is compounded by the fact that a high number of parents with learning disabilities are thought to be unknown to existing services. There is some anecdotal evidence that parents are often worried about having their children removed and thus remain hidden to services, unless the family situation deteriorates and become listed on a Child Protection Plan and/or known to the justice system.

Cornwall Partnership Foundation Trust (CPFT) received around 100 referrals a year. This may be an over estimate because some of these are re-referrals and includes people who get referred but don’t have a clinical diagnosis of a learning disability. Furthermore, the point at which a learning need seems to impact on parenting is often below the threshold of other learning disability services. So many of parents being referred to CPFT are struggling due to learning needs, yet they don’t get any support until their children are neglected and they are on a Child Protection (CP) plan. The trust follows best practice guidance and work hard to try to stop parents falling through service gaps and then presenting in crisis with children on CP plans or in court. Parents with a learning disability and other issues (e.g. mental health, domestic violence, experiences of being in care, trauma and abuse) appear to be most at risk and likely to require safeguarding processes.

To help alleviate these risks, CPFT deliver a range of interventions at high risk groups, as well as provide midwifery training on the identification of parents with learning disabilities and how to make appropriate adjustments when delivering ante-natal and post-natal care. The number of parents with a learning disability may be available from midwifery in the future.
4.7 Independent living

A dominant theme in the development of best practice in health and social care has been the focus on ‘the person’. Think Local Act Personal is a national partnership with the aim of transforming health and social care through personalisation and community based support. From October 2014 individuals who are not in hospital but have complex ongoing healthcare needs will have a right to receive a personal health budget.

A description of person centred planning and independent living is provided by the Councils Community Based Support and Housing Commissioning Framework (Long Term Care Commissioning Team, 2016a). However, the actual number of people living independently remains yet to be fully explored.

4.8 Signposting

We do not know people’s experiences and expectations of sign posting into learning disability services (e.g. any preferences on the provision of easy read or audio information)

5.0 Health, Care and Support Services

Those known to GPs, adult social care (ASC) and CPFT provides an estimated number of people accessing services in Cornwall (Figure 5.0a). These registers include individuals accessing services in Cornwall and out of county placements. GP registers represents the best source for assessing the number of people with a learning disability and known to services. However, due to the nature of register records, it is not possible to identify where services overlap and this estimate does not account for the true prevalence of learning disabilities, which remains unknown.

There are 3,002 people (all ages) registered as having a learning disability with GPs. Around 1,700 people are known to adult social care and 632 access services provided by CPFT. This includes 449 adults with a learning disability and 183 with epilepsy. As previously demonstrated, Cornwall has a higher prevalence of people with learning disabilities when compared to England and the SW.
In line with national projections, the number of people with a learning disability, those with a moderate or severe learning disability (particularly across school age years) and in receipt of services are expected to rise. This may be compounded by levels of challenging behaviour and in the number of people coming into Cornwall with complex needs (i.e. Cornwall is thought to be a net importer (Shankar et al., 2017)). However, little evidence quantifying the number of people with a learning disability coming into Cornwall or the impact of in/out of county placements of those with complex needs.

Additional service pressures, includes an aging population of people with a learning disability (owing to increased life expectancies) and their family and carers. For example, 25% of people with a learning disability only become known to services when their family carers become too old and frail. These trends are likely to increase demand pressures on existing and future services.

A range of local services provide support. Local service model and provision (Shankar et al., 2017) acknowledges (Figures 5.0 & 5.0c) the need to work proactively with:

- capable communities to promote health, well-being and inclusion of people with Learning disabilities at a general population level, thus enhancing social inclusion;
- mainstream services to address the health needs of people with an Learning disability to ensure equality of care and access;
- specialist Teams providing interventions that work collaboratively with partner agencies and which contribute to the creation and maintenance of capable specialist Learning disability services and offer; and
- specialist Interventions that provide person-centred, individually tailored support to maximise a person’s abilities and opportunities resulting in improvements in life expectancy, physical health and emotional well-being

**Figure 5.0b Local service model and provision (Shankar et al., 2017)**
5.1 Social Care

Details on social care provision for children and young people are outlined in the SEND needs assessment, which will be published during 2018. It is intended that more detail on social care activity for adults with a learning disability will be presented in a subsequent update to this needs assessment. This should include people accessing social care services, which are provided by specialist learning disability teams.

Eligibility for social care services is based on assessment of needs for support and risk to health and wellbeing if no support is offered. Support includes:

- residential care for people who cannot live independently;
- specialised supported accommodation for people with more complex needs;
- outreach practical support in the person’s home;
- advocacy services;
- support for carers, including respite breaks; and
- accommodation support.

The Long Term Care Commissioning Team (2016a) provides a up to date description of the type of services available for people with a learning disability. These include for example, long term supported accommodation (LTSA), individual budgets service, and
supported living services (SLS), adult placement / shared lives (accommodation with care and support), day activities, short breaks and residential care.

5.1.1 Transition from children to adult services

Specialist community child and adolescent mental health services (CAMHS) learning disability service provide assessment, advice and treatment for children and young people with severe and complex mental health problems. However, young people with a learning disability transitioning from a range of child services may have other needs that are not met by this service. For this reason transitions are more often facilitated by the special education schools and the Transition Social Workers within CPFT. The Trust is currently investigating the impact of this.

Individual support and transition planning (person-centred transition plans) from childhood into adulthood can improve choice and control for people with a learning disability. This can be used to better support young people with learning disabilities to get jobs and live full lives as adults for example. Valuing People Now highlights the need for all young people to have person-centred transition plans focusing on health, housing, jobs, friends and relationships and social inclusion. In order for this to happen, young people and their families need to receive expert advice and information from the ages of 13/14 years, which should be about the options available to support their future aspirations. The statutory duty to ensure children with a learning disability have person-centred transition plans lies within schools and there should be backing from head teachers to ensure it happens. Further information is available in the SEND needs assessment.

5.1.2 Packages of care

National evidence suggests that adult social care services are being provided for fewer people with learning disabilities, which maybe a result of financial pressures. Like most councils, Cornwall has had to make significant budget reductions in recent years and the situation is predicted to continue. Since austerity began in 2010, the Council has saved nearly £300m, and it is estimated that over the next four years the Council will have to find further savings of around £75m to balance the budget and keep on top of the demand for its services, price and pay inflation, and the continuation of the reduction in Government funding. Further one-off savings or funding will be needed to balance the budget (Cornwall Council, 2017d, Cornwall Council, 2017e). These fiscal challenges mean that local budgets are being cut to make these savings and expected to impact those with a learning disability.

The cost of providing learning disability services in 2015/16 totalled £57.35 million, which included care provision (£47,216 million), learning disability care management staffing (£3,989 million), day services and in house respite (£6,145 million).

The Adult Transformation and Commissioning team are currently undertaking a Fair Cost of Care project to bench mark the cost of care home placements, which may be
followed by a review of supported living funding arrangements. No financial information is available for children services because of the focus on the type of disability where learning disability will not be accurately recorded as the primary reason for receiving support. For example, children may have up to 6 different conditions.

### 5.1.3 Personalised budgets

Government policy emphasises the use of personal budgets and/or direct payments to maximise the capacity of service users and their carers to tailor service packages to personal requirements and tastes. The proportion of adults with learning disability receiving long term support who are receiving direct payments or part-direct payments is significantly lower in Cornwall (14.4% 95%;CI 12.3-16.7) when compared to rates across England (17.4% 95%;CI 17.2-17.6) (PHE, 2016c).

All new people with learning disability being assessed by Adult Care and Support will be offered a Personal Budget as will all individuals having a review. There has been a steady rise in the number of people receiving Direct Payments since the last needs assessment (104 people in August 2011) to present day (Table 5.12a). Those receiving a Direct Payment are likely to increase in line with the projected demographic changes for people with a learning disability. This is likely to be in line with the number of people receiving support that is Council commissioned services and those in residential and nursing homes (Table 5.1.3b).

<table>
<thead>
<tr>
<th>Area</th>
<th>Learning disability</th>
<th>Older People and Physical Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bodmin</td>
<td>133</td>
<td>162</td>
</tr>
<tr>
<td>Liskeard</td>
<td>79</td>
<td>182</td>
</tr>
<tr>
<td>St Austell</td>
<td>109</td>
<td>187</td>
</tr>
<tr>
<td>Truro</td>
<td>83</td>
<td>148</td>
</tr>
<tr>
<td>Camborne</td>
<td>114</td>
<td>141</td>
</tr>
<tr>
<td>Penzance</td>
<td>96</td>
<td>115</td>
</tr>
<tr>
<td></td>
<td><strong>614</strong></td>
<td><strong>935</strong></td>
</tr>
</tbody>
</table>

**Table 5.1.3b**

<table>
<thead>
<tr>
<th>Area</th>
<th>(Long Term Care Commissioning Team, 2016a)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning Disabilities</td>
<td>Council commissioned services 700</td>
</tr>
<tr>
<td></td>
<td>Residential and Nursing Care Home 400</td>
</tr>
</tbody>
</table>
Cornwall Council will continue to develop an individualised support planning process for people, as well as developing and piloting Individual Service Funds allocated to providers in order to achieve person centred outcomes for people. Integrated Personalised Commissioning (IPC) is being led by NHS Kernow, in partnership with the local authorities. The main aspect of this approach is the ‘guided conversation’ which aims to identify outcomes with individuals which, if met through a Personal Health Budget, may avoid them from having to use crisis and emergency services to meet their ongoing needs (Long Term Care Commissioning Team, 2016a).

5.1.4 Living in areas of deprivation

National evidence suggests that people with a learning disability, particularly those with severe and profound multiple disabilities, are more likely to live with a parent and more likely to be living in an area of deprivation. There is currently no local information on area deprivation and populations of people with a learning disability in Cornwall, or the impact this has on health inequalities. This is important to consider because people with a learning disability have high rates of psychiatric illness and are known to live in more deprived areas than the general population. This means that use of community psychiatry is greatest in more deprived areas. If services do not adjust for deprivation, this may lead to further discrimination in an already disadvantaged population (Nicholson and Hotchin, 2015).

5.1.5 Black and Minority Ethnic Groups (BME)

The Equality Act 2010 legally protects people from discrimination in the workplace and in wider society. However, there was no information found to establish if there are any cultural or social barriers to accessing services or under recording in the BME population locally. This may be a result of no data being available at the time of this needs assessment and/or this is not currently routinely monitored.

5.1.6 Carers

Cornwall Council provides support to Carers. This includes information, advice, assessments, group support, befriending and short breaks assistance. This can be obtained via a carers assessment (Cornwall Council, 2017b).

Nationally, there are a reduced number of carers receiving a service. In Cornwall, carers who have received an assessment of their needs may be eligible for a Carers Personal Budget. In 2014/15 2,274 Carers received an assessment and 1,528 received a personal budget. Of these, around 2,166 had a Carers support plan.

Two types of training are available for carers; moving and handling and training to support the Carer in a caring role (available through face to face and e-learning); and Carers Wellbeing training which helps the Carer emotionally and in the development of personal life skills focussing on their wellbeing. An Emergency Carers Card scheme is currently in place and this is in the process of transferring to the central Carers database and register.
Kernow Carers Service is nearing the end of its first contract year. The fundamental change this year is that the service now delivers Carers Assessments, which is a direct result of feedback from carers. Further improvements are being sought in the delivery of personal budgets to expedite the process. The new Carers Service for Cornwall will also be available to help provide support for all unpaid carers of all ages. This is being delivered jointly by Action for Children, working with CRCC and Cornwall’s Family Information Service.

The Adult Social Care Survey, 2015-16 seeks to learn about how effectively services are in helping service users to live safely and independently in their own homes, and the impact that these services are having on their quality of life. However, this is not specifically broken down by the kind and level of disability. Nationally, there has been an increase in the proportion of respondents reporting that having help makes them think and feel better about themselves, which appears to be reflected in Cornwall (NHS Digital, 2016d). The survey provides carers responses to 22 questions at the area level. Despite a low response rate, overall participants said they were satisfied with the care and support services they receive (Table 5.1.6a) (NHS Digital, 2016d).

<table>
<thead>
<tr>
<th>Question 1 - Overall, how satisfied or dissatisfied are you with the care and support services you receive?</th>
<th>Cornwall</th>
<th>Devon</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am extremely satisfied</td>
<td>31.1</td>
<td>28.8</td>
<td>27.5</td>
</tr>
<tr>
<td>I am very satisfied</td>
<td>35.9</td>
<td>37.7</td>
<td>34.1</td>
</tr>
<tr>
<td>I am quite satisfied</td>
<td>26.2</td>
<td>25.9</td>
<td>28.0</td>
</tr>
<tr>
<td>I am neither satisfied nor dissatisfied</td>
<td>3.8</td>
<td>3.9</td>
<td>6.2</td>
</tr>
<tr>
<td>I am quite dissatisfied</td>
<td>1.1</td>
<td>2.0</td>
<td>2.4</td>
</tr>
<tr>
<td>I am very dissatisfied</td>
<td>0.8</td>
<td>0.2</td>
<td>0.8</td>
</tr>
<tr>
<td>I am extremely dissatisfied</td>
<td>1.2</td>
<td>1.6</td>
<td>1.0</td>
</tr>
<tr>
<td>Respondents</td>
<td>265</td>
<td>470</td>
<td>54,710</td>
</tr>
</tbody>
</table>

Other additional surveys that may be of interest includes the; Carers Service Survey concerning re-tendered services (completed in June 2015); Carers Wellbeing Survey (conducted by Healthwatch and still ongoing); and Individual Surveys completed by Cornwall Carers Service as part of the development of the Carers Strategy (Cornwall Council, 2017c). There is also the Cornwall’s Multi Agency Strategy For Young Carers (Children’s Trust Cornwall).
5.2 Primary care

GPs are funded to hold a register of adults with a learning disability. All practices in Cornwall are signed up to keeping a learning disability register. This information has been validated annually by the learning disability community liaison nurses. At the end of 2015/16, there were 3,002 people aged over 14 registered with GPs for having a learning disability. Those registered with a GP as having a learning disability should be offered an annual health check under the Enhanced Service (ES). This was established and informed by national guidance to ensure that people aged over 14 with a learning disability are offered the opportunity to receive a regular, comprehensive health check and a resulting health action plan. All GP practices are now signed up for ES.

5.2.1 Health checks

Preventive strategies such as health checks, health promotion, screening and immunization can help increase life expectancy. For example this may include interventions to decrease mortality arising from preventable causes, such as respiratory infections, circulatory system diseases and accidental deaths (Tyrer and McGrother, 2009).

Trends for the number of people with learning disabilities in England eligible for and receiving a learning disability annual health check show a continual rise to 2014/15 (PHE, 2016d). However, recent data released by NHS Digital show that the number of health checks received decreased during 2015/16, with slightly higher rates nationally when compared to Cornwall (Table 5.2.1a). The number of health checks carried out also varies considerably across Cornwall, although this may be influenced by the small number of people on some GP registers and potentially some practices carrying out more annual health checks than those on the GP register (Figure 5.2.1a).

<table>
<thead>
<tr>
<th>Year</th>
<th>Eligible</th>
<th>Checks</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cornwall</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2013/14</td>
<td>2491</td>
<td>1191</td>
<td>47.8%</td>
</tr>
<tr>
<td>2014/15</td>
<td>2707</td>
<td>1738</td>
<td>64.2%</td>
</tr>
<tr>
<td>2015/16</td>
<td>2998 *</td>
<td>943</td>
<td>31.5%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Year</th>
<th>Eligible</th>
<th>Checks</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>National</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2013/14</td>
<td>214,352</td>
<td>94,500</td>
<td>44.1%</td>
</tr>
<tr>
<td>2014/15</td>
<td>197,451</td>
<td>124,785</td>
<td>63.2%</td>
</tr>
<tr>
<td>2015/16</td>
<td>250,984 *</td>
<td>97,706</td>
<td>38.9%</td>
</tr>
</tbody>
</table>

“*” Value from QOF learning disability Register (Historically QOF Register is higher than HSCIC Register)

Annual differences in the number of health checks received may be due to several reasons. Due to a lack of data on the total number of people eligible for a health check.
check in 2015/16, we used figures from the QOF learning disability register, which is historically higher than the HSCIC register. There was a corresponding rise in the number of people being registered as having a learning disability (this may partly be due to change in those aged 14 being eligible during 2014/15) and a reduced number receiving a health check when compared to 2014/15 (PHE, 2016d). A similar downward trend was shown for England, thus it is also possible that there are data quality and reporting issues affecting the number of health checks received. In addition, NHS Digital cannot extract information from GP practices using ‘Microtest’, which is used widely across Cornwall. Hence the number of completed health checks is likely to be underestimated. Furthermore, it is also possible that this may also be a combination of the voluntary participation of people with learning disabilities and/or GP practices not prioritising learning disability health checks because they are an optional requirement. These factors require further research.

Figure 5.2.1a Location of care homes, GP practices & proportion of health checks completed (ages 14+ years)

Future work should also investigate the coverage of health checks across Cornwall, which appears to vary greatly by area. The lower rates of health checks could put people at greater risk of common diseases such as circulatory, respiratory diseases and neoplasms. Adopting the recommendations of a recent qualitative study (Healthwatch, 2013) may help increase the uptake of health checks among people with learning disabilities. The study recruited 52 people who had a recent Annual
Health Check, and despite some limitations, there were several recommendations made to;

- 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.

It is also not clear whether meaningful health action plans are produced as a result of the annual health checks or the effectiveness of health checks in identifying unmet health needs. This forms part of the formal training, which primary care liaison nurses provide for those who conduct health checks. It may be possible to obtain further information from primary care liaison nurses who sit in on some of the health checks being conducted across Cornwall.

5.2.2 Dental care

People with learning disabilities also have poorer oral hygiene status and a higher prevalence of dental caries and periodontal disease. As a consequence, poor oral health not only affects the physical well-being of these groups but also has a marked impact on their quality of life, overall health and self-esteem. Access to oral health care and needs of people with learning disabilities are complex and multi-faceted (Naseem et al., 2016). Further research is needed to identify the most appropriate care and support model for people with learning disabilities. This is important to consider because the uptake of dental check-ups is lower than the general population and dental work tends to be reactive rather than preventative. There is some anecdotal evidence that the provision of a liaison nurse locally could help support people with a learning disability and promote oral health in Cornwall, however, there is insufficient funding for an additional liaison nurse. The Health Promotion Service (see below) have a rolling programme for promoting dental hygiene at schools, day centres and community centres etc. to help promote the importance of attending a dentistry. However, it is not known how many people with a learning disability in
Cornwall access a mainstream dental practice or Special Care Dentistry service (depending on level of disability and oral health need).

5.2.3 Sensory Impairments

It is known that people with learning disabilities have a high level of sensory impairment issues and unmet health need related to eyes and hearing (Emerson et al., 2011), but no information exists locally on the impact of sensory impairments. It may be possible for CPFT to record levels of sensory impairment from their case load and/or to obtain data via read codes on GP records, however, this requires further information.

5.2.4 Immunisation against seasonal influenza (NHS Digital, 2017)

The national Flu Plan prioritises people with learning disabilities for flu immunisation as a clinically at risk group. This includes individuals with chronic neurological disease aged 6 months or over as per the seasonal influenza enhanced service. Promotional material is available for GPs, parents, adults, social care providers and head teachers to encourage the uptake of vaccinations (PHE, 2014a). The Seasonal influenza and pneumococcal immunisation enhanced service specification programme is directed at GP practices delivering vaccination and immunisation services in England (NHS, 2014).

The 2014/15 Census on learning disabilities (NHS Digital, 2017) reported the number of patients recorded on their general practices’ Learning Disabilities Register who had an immunization against seasonal influenza in the period 1 September to 31 March in the 12 months to the Reference Year End Date. At this point in time, immunization coverage across England during 2014/15 was 40.80% across all age groups (NHS Digital, 2017). Census data shows that Cornwall has lower participation rates (Table 5.2.4a), particularly among men.
Table 5.2.4a Immunisation against seasonal influenza data from the learning disability census (NHS Digital, 2017)

<table>
<thead>
<tr>
<th>Age band</th>
<th>Female Number of patients</th>
<th>Female %</th>
<th>Male Number of patients</th>
<th>Male %</th>
<th>Male &amp; female Number of patients</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 TO 9</td>
<td>2</td>
<td>20.00</td>
<td>1</td>
<td>25.00</td>
<td>3</td>
<td>21.43</td>
</tr>
<tr>
<td>10 TO 17</td>
<td>7</td>
<td>12.96</td>
<td>5</td>
<td>4.90</td>
<td>12</td>
<td>7.69</td>
</tr>
<tr>
<td>18 TO 24</td>
<td>11</td>
<td>11.58</td>
<td>21</td>
<td>10.24</td>
<td>32</td>
<td>10.67</td>
</tr>
<tr>
<td>25 TO 34</td>
<td>35</td>
<td>24.82</td>
<td>30</td>
<td>13.33</td>
<td>65</td>
<td>17.76</td>
</tr>
<tr>
<td>35 TO 44</td>
<td>49</td>
<td>34.27</td>
<td>35</td>
<td>25.74</td>
<td>84</td>
<td>30.11</td>
</tr>
<tr>
<td>45 TO 54</td>
<td>44</td>
<td>36.67</td>
<td>66</td>
<td>35.29</td>
<td>110</td>
<td>35.83</td>
</tr>
<tr>
<td>55 TO 64</td>
<td>45</td>
<td>43.69</td>
<td>54</td>
<td>40.60</td>
<td>99</td>
<td>41.95</td>
</tr>
<tr>
<td>65 TO 74</td>
<td>26</td>
<td>55.32</td>
<td>36</td>
<td>59.02</td>
<td>62</td>
<td>57.41</td>
</tr>
<tr>
<td>75 +</td>
<td>10</td>
<td>47.62</td>
<td>13</td>
<td>61.90</td>
<td>23</td>
<td>54.76</td>
</tr>
<tr>
<td>All ages</td>
<td>229</td>
<td>31.20</td>
<td>261</td>
<td>24.30</td>
<td>490</td>
<td>27.10</td>
</tr>
</tbody>
</table>

During the same period, immunisation reports for Cornwall show that these rates are lower than those in the general population. While no data is available for people with learning disabilities, 70.4% of people aged over 65 were protected against seasonal influenza, although this reduced to 49.4% in at risk patients aged between 6 months and 65 years (PHE, 2017c).

5.3 Community care

Nationally, there has been a low uptake of health promotion or screening in this population, specifically with respect to assessing visual or hearing impairments, dental care, cervical smear tests and breast self-examination and mammography (Emerson et al., 2011). Although, there is a lack of significant empirical evidence about the uptake of bowel, AAA and diabetic retinopathy screening by people with learning disabilities, but there is some local data from the South West showing a lower uptake (Turner et al., 2013).

Locally, community care comprises of the Screening Liaison Nurse Team, which includes two Screening Liaison Nurses (SLNs). Their role is to increase the uptake of the adult screening programmes for people with learning disabilities in Cornwall, which differs from other areas. Every person with a learning disability is invited to participate in the national screening programmes when reach the appropriate age. Cornwall Pathways for each Screening Programme (abdominal aortic aneurysm, bowel, breast and retinopathy pathways) illustrates how people with learning disabilities are identified and the extra support that is available if needed. Cornwall appears to be screening a higher proportion with people with learning disabilities. This approach provides an example of best practice being delivered across Cornwall to address the unmet health needs among this population.
The team offers support to individuals, their families and carers with any form of hospital admission or appointments before, during and after hospital visits as needed. Support can involve explanations of procedures, providing accessible information as well as supporting staff to ensure they comply with the Mental Capacity Act and help ensuring safe discharge.

The team also work closely with the hospital staff providing advice to ensure that reasonable adjustments to patient care have been considered. The team provide training as part of the mandatory equality and diversity training for all new staff, except for medical doctors.

The team operates an open referral system and receives referrals from wards, families, carers, and professionals. They rely on other people being aware of the services and referring patients to them.

### 5.3.1 Breast screening

There is a process in place with the programme staff who inform the SLNs when any woman with a learning disability needs to go for assessment. Women can be offered extra support through this process.

In Cornwall, the uptake of women with learning disabilities attending this screening has risen. Service data between 1st April 2014 and 31st March 2017 for screening figures show a 72% attendance rate of women with learning disabilities, which is above the NHS Cancer Screening Programme’s minimum standard of 70 per cent and comparable to screening rates among the general population (NHS Digital, 2016a).

Higher rates of attendance were also reflected in the 2014/15 Census on learning disabilities (Table 5.3.1a). Although the Census shows slightly lower attendance rates, this is likely to be due to limitations of the study. The Census reports the number of patients recorded on their general practices Learning Disabilities Register being female aged 50 to 69 who received breast cancer screening in the five years prior to Reference Year End Date. According to the 2014/15 census, a higher proportion of women attended screening when compared to England.
Table 5.3.1a  Breast Cancer Screening census data from the learning disability census (NHS Digital, 2017)

<table>
<thead>
<tr>
<th>Age band</th>
<th>% of women with a learning disability attending breast cancer screening across England</th>
<th>% of women with a learning disability attending breast cancer screening across Cornwall</th>
</tr>
</thead>
<tbody>
<tr>
<td>50-54</td>
<td>44.04</td>
<td>58.62</td>
</tr>
<tr>
<td>55-59</td>
<td>57.21</td>
<td>62.96</td>
</tr>
<tr>
<td>60-64</td>
<td>55.95</td>
<td>71.43</td>
</tr>
<tr>
<td>65-69</td>
<td>54.56</td>
<td>61.29</td>
</tr>
<tr>
<td>Total</td>
<td>51.78</td>
<td>63.54</td>
</tr>
</tbody>
</table>

5.3.2 Cervical screening

GP practices provide this screening. To improve access to this screening, the SLNs have worked closely with Public Health England to create the South west cervical screening pack. This pack contains; guidance for professionals; a new postponement request form; accessible information on what happens at a screening appointment; accessible information on signs and symptoms of cervical cancer; best interest decision guidance; ideas for maximising capacity to consent to screening; and a family/carer letter explaining why it is good practice to postpone rather than permanently cease a woman from the programme who cannot manage to participate in cervical screening.

The SLNs present the cervical sample takers 2-day course and their following annual update courses, which is for health professionals training to take cervical samples. This ensures that each new screener/current screener gets to meet the SLNs and understand what support and resources are available.

Feedback from practice nurses has highlighted that successful joint clinics between SLN’s and screeners have increased the screeners understanding and confidence when working with women with learning disabilities.

There have been changes to the call/recall services. In the past, SLNs had a communication system with Shared Business services (SBS) in Wiltshire who ran the call/recall for Cornwall cervical screening. The SBS staff always passed on any requests for permanent ceasing to the SLNs so they could contact the surgery and assess the appropriateness. SLNs are no longer able to phone for further information and requests are only dealt with via email, which can cause delays.

All request forms received by call/recall from patients to be ceased from the programme are now forwarded to public health, and then the screening and immunisation manager informs the SLNs of any ceasing requests. SLNs have not been notified of any women with learning disabilities being ceased permanently from the
cervical screening programme since the forms have been sent to the screening and immunisations programme manager.

The Census on learning disabilities collected information on the number of patients recorded on their general practices' Learning Disabilities Register and who are eligible for cervical cancer screening being female aged 25 to 64 with no history of hysterectomy, on whom an adequate cervical smear test has been performed in the five years prior to Reference Year End Date. Cornwall appears to be performing better than national estimates; however, screening rates are lower than those among the general populations (Table 5.3.2a). In 31 March 2016, the percentage of eligible women (aged 25 to 64) who were recorded as screened adequately within the specified period was 72.7 per cent. This compares with 73.5 per cent at 31 March 2015 and 75.7 per cent at 31 March 2011 (NHS Digital, 2016b).

<table>
<thead>
<tr>
<th>Age band</th>
<th>% of women with a learning disability receiving cervical smear test across England</th>
<th>% of women with a learning disability receiving cervical smear test across Cornwall</th>
</tr>
</thead>
<tbody>
<tr>
<td>25-34</td>
<td>30.73</td>
<td>35.46</td>
</tr>
<tr>
<td>35-34</td>
<td>32.95</td>
<td>38.73</td>
</tr>
<tr>
<td>45-54</td>
<td>30.75</td>
<td>43.75</td>
</tr>
<tr>
<td>55-64</td>
<td>24.91</td>
<td>34.74</td>
</tr>
<tr>
<td>Total</td>
<td>30.21</td>
<td>38.16</td>
</tr>
</tbody>
</table>

5.3.3 Bowel Screening

All surgeries are asked to identify their patients with learning disabilities who have not participated in the screening to the SLNs. Some surgeries do this in a timely manner and others do not. The GP surgeries hold the information on uptake figures for their own patients.

The SLNs offer to visit patients at home to explain why bowel cancer screening is important and describe how to complete the test kit if people want to participate. They order new test kits for patients and try to ensure that patients get any additional help if it is required.

The SLNs have worked with the Southern Bowel Screening hub on a project to try to get patients with a learning disability identified via the additional notes on the computer system. If any of these patients get a positive result the Specialist Screening Practitioners (SSPs) will then know in advance and can contact patients and carers to see what reasonable adjustments might need to be made. 80% of Cornwall’s
GP surgeries supplied the Hub with the information requested on the age of patients in the bracket for bowel screening.

There is a resource pack containing accessible information, advice on maximising capacity and best interest advice for the SSPs so they have information when they have a patient with learning disabilities.

The 2014/15 Census on learning disabilities shows that Cornwall also has higher bowel cancer screening rates than across England (Table 5.3.3a). This data provided the number of patients recorded on their general practices’ Learning Disabilities Register and aged 60 to 69 who are eligible for colorectal cancer screening, and who have a record of having a colorectal cancer screening result recorded in the five years prior to Reference Year End Date.

<table>
<thead>
<tr>
<th>Age band</th>
<th>% of women with a learning disability attending colorectal cancer screening across England</th>
<th>% of men with a learning disability attending colorectal cancer screening across England</th>
<th>% of women with a learning disability attending colorectal cancer screening across Cornwall</th>
<th>% of men with a learning disability attending colorectal cancer screening across Cornwall</th>
</tr>
</thead>
<tbody>
<tr>
<td>60-64</td>
<td>66.45</td>
<td>64.75</td>
<td>83.67</td>
<td>78.13</td>
</tr>
<tr>
<td>65-69</td>
<td>71.23</td>
<td>73.28</td>
<td>80.65</td>
<td>74.42</td>
</tr>
<tr>
<td>Total</td>
<td>68.61</td>
<td>68.52</td>
<td>82.50</td>
<td>76.64</td>
</tr>
</tbody>
</table>

### 5.3.4 Diabetic Retinopathy Screening

All newly diagnosed patients with diabetes are contacted in a timely manner with the offer of extra information/support if needed. The screening administration team contact the SLNs if any patients with learning disabilities need to go in to the assessment clinic and this means extra support is offered. Additional information on the uptake of retinopathy may be available from CPFT, but this requires further investigation.

### 5.3.5 Abdominal Aortic Aneurysm Screening (AAA)

The SLNs are notified by the AAA screening programme manager about patients with a learning disability who do not attend. The SLNs gather information so patients can be offered any reasonable adjustments or desensitisation work that needs to be done.
for screening to be completed. A local photo story has been completed in conjunction with the Peninsula AAA screening centre of exactly what happens at AAA screening appointment. This has large step by step photos and will help patients and carers understand exactly what happens at a screening appointment. Additional information may be available from CPFT, but this again requires further investigation.

5.3.6 Reasons why people with learning disabilities don’t attend or participate

Recent reviews have highlighted a number of barriers to participation (Turner et al., 2013, Turner et al., 2015). The following were highlighted by SLNs that lower screening attendance rates;

- Nationally screening services rely on everyone being able to be treated the same. This is reflected in the letters/information they send out, and reliance that people have the capacity to make a decision around screening and the time slots given for screening appointments.
- Screening programme staff have time constrictions (set at a national level), are restricted to working in their own environment and generally don’t have the expertise of working with people with learning disabilities.
- The systems used by the screening services do not identify patients with learning disabilities. Without this knowledge, the screeners cannot make the appropriate reasonable adjustments.
- People with learning disabilities are identified to the screening programme and SLN’s by GP surgeries. People with learning disabilities are then told about screening in a way people can understand and shown what is going to happen and why.
- Patients know there is a choice and when they don’t have capacity to make their own choice; a best interest process is followed.
- Information is not sent out in an accessible format for the cervical and bowel screening programmes.

To help overcome some of the barriers, SLNs carry out face to face consultations in a home environment, which helps screeners make the reasonable adjustments needed. Due to the early identification of patients with learning disabilities, patients in Cornwall are now getting information that is easier to understand for breast cancer, abdominal aortic aneurysm (AAA), and diabetic retinopathy screening. SLNs are included in a working group for Public Health England to ensure that good quality accessible information is available nationally for all screening programmes. Furthermore, Turner et al. (2013) provides a toolkit for improving local strategies for improving the uptake of cancer screening. Data on immunisation and cancer screening is monitored by Public Health England, but data on people having learning disabilities is not identifiable from national/regional data.
To help further our knowledge on the barriers and facilitators for screening participation, further research is needed to explore the views of people with learning disabilities and the uptake of screening programmes.

5.4 Health promotion

People with learning disabilities have more health needs compared to the general population, including high prevalence of overweight and obesity, poor diet and often less access to physical activity opportunities and meaningful activities.

Good health begins with promoting wellbeing and preventing ill health. The Health Promotion team carry out regular events to promote healthier lifestyles across Cornwall and reduce inequalities. These include Fresh, Healthy Cooking Groups and Eat Well for Less, Big Park Day and CHAMPS (the Cornwall Health and Making Partnerships) on the move.

CHAMPS are a team consisting of people who have a learning disability. The team was established to help to make sure that people with a learning disability and/or autistic spectrum conditions get equal access to health services. Health promotion and the CHAMPS team help with:

- Checking Health Services
- Learning Disability Awareness and Easy Read Training
- Speaking Up
- Making Easy Read
- Promoting Healthy Lifestyles
- Safe Places
- Dental hygiene

The CHAMPS team have completed their programme of training for the peer support project developed by the Community Engagement Team at Peninsula Dental Social Enterprise (PDSE); a dental ambassador scheme. Training included areas such as oral hygiene, tooth brushing, the importance of fluoride, healthy eating, reducing sugar intake and accessing dental care. As part of their ongoing work across Cornwall, the CHAMPS now plan to take oral health knowledge to special schools, health centres and adults with learning disabilities at colleges and workplaces (Dental, 2017).

Health promotion conduct a range of health services, including health checks, stop smoking, healthy weights courses and a healthy weight programme for adults etc. Over the last year, there appears to be a limited number of people with learning disabilities referred into these programmes. For example, during 2015/16 a total of 17 people with learning disabilities accessed the health weights programme. Current work is underway to make these programmes more accessible to people with a learning disability. Further information may be available in the future.
5.5 Secondary care

5.5.1 Inpatient care
Public Health England recently published secondary analyses of people with learning disabilities or autism in hospital (PHE, 2015b). According to the 2015 Census on people with learning disabilities receiving in patient care (30th September), there were 3,000 inpatients receiving treatment or care in a facility registered with the Care Quality Commission at midnight on the 30th September 2015 in England. Of the 3,000 patients, 2,500 patients (83%) were subject to the Mental Health Act on census day, and 510 patients (17%) were receiving inpatient care on an informal basis (NHS, 2015a). The South West is a net importer for patient care when comparing the number of patients. In Cornwall, there were less than 5 inpatients and 10 residing at their place of residence, but the number of patients coming into or leaving the county was suppressed (Health and Social Care Information Centre, 2016). Further regional analyses are available for other factors such as legal status, treatment reasons, risks, incidents, medication, advocacy, care plans and length of stay.

5.5.2 Acute Liaison Nurse Service (ALNS)
The Royal Cornwall Hospital Learning Disabilities service comprises of ALN Nurses who provide help and assistance to children and adults with a learning disability or autism when visiting the Trusts hospitals in Penzance, Truro and Hayle. Their role is to help patients with a learning disability (with an outpatient appointment) to move through the hospital system more smoothly and making reasonable adjustments to care. They can also help with issues pertaining to the mental capacity act and best interest decisions.

Once again, 2016 has seen an increase in attendance to hospital for patients and their families (Cooper, 2016). Needs are met by the ALN team, which comprises of 1 WTE Band 7, Acute Liaison Lead Nurse (currently a job share), and 2 WTE Band 6 Acute Liaison Nurse. The Service undertakes a range of education and practice development activities aimed at enhancing the knowledge, skills and awareness of hospital staff.

The ALN service works very closely with Patient Advisory Service (PALS). They ensure that any concern or complaint raised by or on behalf of a patient with a learning disability and or autistic spectrum disorder is looked into by a member of the ALN team. This year there have been two complaints raised and the service has supported the staff on the ward area and the patients / family. To ensure lessons are learnt Trust wide, examples from complaints form part of the ALN service, development and education sessions.

The service saw 1278 patients from January 2016 to December 2016; this equates to a 15% increase from the previous year (Table 5.5.2a). The contacts recorded ranged from telephonic advice, to daily support (face to face / hands on) and advice during a hospital stay. Table 5.5.2b shows an increase in the contact with children (Cooper, 2016).
Table 5.5.2a  Total number of children seen by the acute liaison nurse team between 2014 and 2016 (Cooper, 2016)

<table>
<thead>
<tr>
<th>Total number of patients seen</th>
</tr>
</thead>
<tbody>
<tr>
<td>1400 Patients in 2014</td>
</tr>
<tr>
<td>1200 Patients in 2015</td>
</tr>
<tr>
<td>1000 Patients in 2016</td>
</tr>
</tbody>
</table>

Table 5.5.2b  Total adult and child patients seen by the acute liaison nurse team between 2015 and 2016

<table>
<thead>
<tr>
<th>Adult vs Child Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adults</td>
</tr>
<tr>
<td>890 (81.95%)</td>
</tr>
<tr>
<td>1003 (78.48%)</td>
</tr>
</tbody>
</table>

5.5.3 End of life / palliative care

Little is known about the extent or quality of end of life care across Cornwall. Moreover, concerns have been raised about a lack of understanding about choices and options on reaching end of life. In Cornwall, there are plans to enhance the Treatment Escalation Plan (TEP) instead of adopting ReSPECT described above. It is not clear whether the number of TEPs on people with learning disabilities is collected and assessed locally.
When compared to rates across England and the control group, there were a lower number of people with a learning disability residing in Cornwall and registered as being in need of palliative care (Table 5.5.3a). Furthermore, there was only a record of men being registered as in need of palliative care and support. There were 0.49%, 0.44% and 1.07% of adults in age bands 18 to 24, 25 to 24 and 45 to 54 years, respectively.

### Table 5.5.3a  Number of patients with a learning disability and who have another diagnosis or receiving treatment, 2014/2015 Census on learning disabilities (NHS Digital, 2017)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Prevalence of diagnosis, % all age groups</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>England</td>
</tr>
<tr>
<td>Registered as being in need of palliative care and support</td>
<td>0.30</td>
</tr>
<tr>
<td>Control</td>
<td>Learning disability</td>
</tr>
<tr>
<td>Learning disability</td>
<td>0.30</td>
</tr>
</tbody>
</table>

### 5.6 Cornwall Partnership Foundation Trust (CPFT)

The Trust provides specialist learning disability services across Cornwall, involving an interaction between social care, adult autism, GPs, Kernow Clinical Commissioning Group and Royal Cornwall Hospital Trust. The service includes allied health professionals, clinical psychology, primary care liaison nurses, adult learning disability community health teams, epilepsy service, Intensive support team, and mental health liaison.

The Intensive support team (challenging behaviour, prevention) provides behaviour support, occupational therapy (OT), speech and language therapy (SALT), physiotherapy, psychological assessment and treatment, psychiatry diagnosis and support, and an epilepsy service (Shankar et al., 2017).

In 2016/17, there were 449 adults with a learning disability and 183 with epilepsy accessing CPFT services. There were 74 people known to the service for having profound multiple learning disabilities and 68 with complex needs. Of these, 46 people with PMLD and 39 with complex health needs are currently being actively supported by the community teams. This constitutes about 24% of the current team caseloads. Some of these are also open to the Specialist Epilepsy Service. Of those open to the teams, 32 are eligible for CHC (continuing health care) funding and, therefore, remain continuously open to the team for care co-ordination. In 2015, the epilepsy service received 65 referrals and discharged 64 patients. There are currently 37 on the caseload. Five of those are out of county placements care coordinated by the Intensive Support Team, and the team are currently developing plans to discharge a
further three people from hospital. The number of referrals, caseload information and future provision information is available from Shankar et al. (2017).

Those placed out of county will receive local health services that may not be adequately resourced to meet their needs. Likewise, people with learning disability from other counties placed in Cornwall will access our primary care, secondary and sometimes specialist healthcare, however, there appears to be limited evidence to quantify this impact on healthcare provision. The majority of out of county placements are due to the complexity of the service users’ needs and / or the lack of specialised suitable facilities within the county (Brigham and Cohen, 2012). Improved monitoring of people placed into Cornwall is required.

Based on population projections, the number of adults with PMLD is predicted to rise. Around one third of the Community Learning disability caseload (approximately 100 clients) is related to people with Learning Disability and behaviours that challenge (Shankar et al., 2017), which roughly corresponds with previous projections. The combined pressures of the projected increase in the number of people with moderate to severe learning disabilities and levels of challenging behaviour may impact services in the future.

A range of work is being conducted by CPFT to help reduce health inequalities among people with a learning disability. For example, to help address concerns over the over prescribing of anti-psychotic and/or anti-epileptic medicine, the “Purple Book” has been developed locally and available to patients and their family/carers to help manage prescriptions. The epilepsy service (current caseload of around 200 people with a potential caseload of 1,000 people) provides a countrywide specialist service. They are piloting a Telehealth service as recognition of ensuring that the vulnerable-well need to remain safe. There are also a number of service changes and developments, which are further described in the strategy document (Shankar et al., 2017) and includes the following areas;

- The allied health professions
- Clinical psychology
- Primary care liaison nurses
- Adult learning disability community teams
- Learning disability specialist epilepsy service
- The intensive support team
- Mental health liaison

CPFT are currently piloting the monitoring and reporting of the Health Equality Framework (HEF) (NDTi, 2013), which is an outcomes tool measuring the determinants of health inequalities. While this provides a usual mechanism to understand the impact of services, the tool is seen by some as not being sensitive enough to show the effect of services on patient outcomes. Other outcome measures (BPI-s, QOMID and TOMS) are being trialled for other clinical care pathways (btc,
dementia, PMLD). HEF as an outcomes tool would be more effective if it was used by all services, including health and social care.

5.6.1 Number of adult referrals to CPFT

On average, there are 64 adult referrals made to CPFT each month for learning disabilities and learning disability with epilepsy (Figure 5.6.1a), which are from mainly white British origin (Figure 5.6.1b). There were slightly more referrals of men (Figure 5.6.1c-e) and majority of referrals were made in adults aged 25+.

Figure 6.6.1a Number of referrals of adults with learning disability or epilepsy to CPFT

![Graph showing number of referrals of adults with learning disability or epilepsy to CPFT]

Figure 5.6.1b Referrals to CPFT by ethnicity for adults with learning disability and learning disability with epilepsy

![Graph showing referrals to CPFT by ethnicity for adults with learning disability and learning disability with epilepsy]
Figure 5.6.1c  Referrals to CPFT by gender for adults with a learning disability

Figure 5.6.1d  Referrals to CPFT by gender for adults with a learning disability and epilepsy
5.7 Cornwall Sports Partnership

Over the past three years Cornwall Sports Partnership has delivered activity to 2,700 participants with a learning disability. These have taken place in various settings such as Day Centres, Events, Community Groups, Leisure Centres, Private Providers and Clubs. The Special Olympics Cornwall club (an affiliated SOGB branch club) was established from the three year programme. The Special Olympics Cornwall club is available for children and adults with a learning disability to take part in a range of sports. For example, every first Saturday of each month there is a Super Hub Club at Truro College, which includes a range of activities; badminton, boccia, basketball, archery, tennis, cricket, football, new age curling and bowls. Other clubs are available throughout Cornwall offering a range of activities. Special Olympics Cornwall now has a membership of 160+ athletes that take part in activity at least 1x30 minutes per week. As a result of being active and playing a sport, individuals have said that they feel more energised, have a reason for getting up and getting out and have a better social relationship with new people. Cornwall Sports Partnership is also held the SOGB National Summer Games with 50 athletes and volunteers on the 7th of August 2017.

5.8 Advocacy, voluntary and community support

Advocacy supports people to speak up and represent their best interests. Advocates aim to help people make positive changes and realise their rights as citizens. Issues that frequently require support include housing, employment, finance and relationships. Many issues require detailed and intensive support.

Cornwall Council, NHS Kernow and the Council of the Isles of Scilly jointly commission contracts for independent advocacy services in Cornwall. The service provider SEAP commenced on 20 June 2016 and mobilised in the first year, following the statutory duties in the Care Act to provide independent advocacy to people that have difficulty
understanding information during the social care assessment, review and support planning process.

There are also voluntary sector services that provide help to people with learning disabilities to be part of the local community. For example, Volunteer Cornwall delivers the Volunteering In Vulnerable Adults (VIVA) service that supports people with learning disabilities, physical disabilities, mental health needs and autism to access and maintain volunteering opportunities (e.g. in charity shops, animal rescue centres, gardens and cafes).

Cornwall Council hosts an up to date web page that provides information on the Learning Disabilities Partnership Board, as well as, provide a link to Support in Cornwall that provides information on services available for children and adults with a learning disability (Cornwall Council, 2017f).

Since austerity began in 2010 the Council has saved nearly £300m, and it is estimated that over the next four years the Council will have to find further savings of around £75m as set out above. This has had a big impact on the services commissioned from the voluntary and community sector, and will continue to do so as further budget reductions are made.

5.8.1 Learning Disability Partnership Board (Cornwall Council, 2017f)

Cornwall Council acts as lead agency for the commissioning and assessment of social care and specialist health services for people with learning disabilities locally. Cornwall Council and Kernow Clinical Commissioning Group have a commitment to work in partnership to improve the lives of people with a learning disability.

The Learning Disability Partnership Board helps take forward local priorities as required in the White Paper Valuing People Now. The Learning Disability Partnership Board meets regularly and is chaired by a member of the council and a person with learning disabilities. The group is made up of family carers and people with learning disabilities and representatives from the NHS, local authority adult social care and housing, other support and service providers as well as voluntary organisations.

The aim of the partnership board is to; provide a voice for people with learning disabilities and their carers; influence local plans and wider strategies to improve access to mainstream services; and improve inclusion in the community locally.

5.8.2 Healthwatch Cornwall (Healthwatch Cornwall, 2017)

The Learning Disability Partnership Board is facilitated by Healthwatch Cornwall, who aim to inspire positive change in Cornwall’s health and social care through effective public engagement. Healthwatch are responsible for the administration and support of the Learning Disabilities Partnership Board under an additional contract with Cornwall Council. While taking over the Board was challenging, Cornwall People First was able
to input and support the restructuring of the board to meet the needs of people with a learning disability. Healthwatch are committed to ensuring that self-advocates continue to input into this meeting and is vital to have first-hand experiences from people with learning disabilities, however supporting the individuals to attend and take part is difficult.

5.8.3 Cornwall People First
Cornwall People First is a user-led self-advocacy charity for adults with learning disabilities throughout Cornwall. They support people to speak up for themselves and work closely with services to improve the way things are delivered.

Cornwall People First has Forum meetings all over Cornwall where people with learning disabilities speak up about things that are important to them, have fun, meet old and new friends, share information, learn new skills, meet visitors like councillors or liaison nurses, visit places in the community like the fire station and connect with their communities.

At every Learning Disability Partnership Board meetings, Cornwall People First summarises the feedback that they have gathered at the forums. This often provides the basis for discussion and for deciding future issues for the Board to look at. The main issues raised during 2016/17 for example, have been around transport - in particular the use of bus passes and the issues with regards to renewal – and with regards to social care assessments and levels of support. If any further action is required, this is recorded against any of the issues raised and then tracked through the Board meetings.

Due to reduced Government funding, as well as an increase in demand and statutory duties related to independent advocacy, the budget allocation for self-advocacy from Cornwall Council has been reduced from £120,000 to £50,000 per annum over the last few years. This poses challenges for learning disability services and for people who live more independently and rely on self-advocacy services. Current gaps in self-advocacy have also been raised via the Learning Disability Partnership Board (e.g. help and support in completing forms). For example, reduction in funding has reduced the number of staff from 10 to 4 people, which equates to two full time posts across Cornwall. This is likely to result in reduced outreach and 1:1 activity to reduce costs, and has had an impact on the up keep of updates published via their website and Facebook etc. (Learning Disability Partnership Board meeting, 19th April 2017).

5.8.4 Staying Safe
Safe Places is a national initiative that has been set up locally (Cornwall Council, 2017h) to help people with learning disabilities and provide a place to go if feeling scared or are at risk while they are out and about in the community and need support right away. People who might need to use Safe Places carry a Safe Places card with
emergency contact details. If help is needed, public places like shops, community centres and libraries are available. These are highlighted by having a Safe Places sticker in their window.

6.0 Community Voice

6.1 Stakeholders
Stakeholders can include people with learning disabilities, carers and wider family networks, those working in the healthcare or other public sectors, and voluntary groups. This section provides an opportunity for stakeholders to express their views on local services, for example, and any future challenges that may affect people with learning disabilities. The following sections provide a summary of some consultancy work conducted by Cornwall Council and complaints. It is anticipated that this further research will be undertaken to further investigate the views, experiences and aspirations of key stakeholders in Cornwall.

6.2 People with a learning disability
Support Services for adults with learning disabilities range from: mainstream to specialist health, social care, housing, employment, voluntary and other support services. However, the special needs of people with learning disabilities are yet to be met in Cornwall.

As previously discussed, promoting more independent living and supported living accommodation is important to improve the health and wellbeing of people with learning disabilities. Many providers have been promoting this approach for some time and the following aims to provide an overview of this work in Cornwall.

Findings from a Care at Home engagement event with people with learning disabilities, family/carers and providers (Cornwall Council, 2017a) showed an increase need for independent living. Aspirations described by participants included having a home and ‘normal’ life, feeling safe, ability to socialise with friends and family, having a choice and can do hobbies and activities, finding paid employment, to be accepted by the community and have a say in support plans. However, several barriers were expressed, including money, discrimination, feeling unsafe, delays in processes, regular transport, access to appropriate housing, impact on work benefits and family being worried about living alone. Well trained teams, good communication at all levels, development of independent living skills (cooking and going out), community awareness (e.g. organising coffee mornings), improved transport, walking and cycling, improved community links and assistive technology and alternative therapies are required. Based on engagement, the commissioning intentions include the aspiration to achieve following outcomes;
• **My Housing** - I choose who I live with and where I live. I own or rent my home and maintain my tenancy
• **My Support** - I plan my own support
• **My Health and Wellbeing** – My physical health, mental health and emotional wellbeing needs are met
• **My Services** - People who support me listen to my views
• **My Choices, Rights and Responsibilities** - I understand my rights, responsibilities and choices
• **My Community Activities** - If I choose to I can take part in community groups and activities
• **My Money** – I understand my money and bills
• **My Safety** – I feel in control and safe
• **My Relationships** – I understand relationships and choose and maintain my friendships and relationships

The benefits of more independent living have been demonstrated by recent case studies. These were collected by the Adult Transformation and Commissioning Team following a recent move from residential care into independent living with support from Hendra. Hendra provides individual support plans, which aim to support people with learning disabilities by giving more choice and control over their own lives. As well as encourage people to have a belief in reaching their full potential regardless of their ability within a structured, holistic environment. Despite there being no long-term evidence, initial findings from Hendra supports more independent living to improve health and wellbeing (Table 6.2a). Recent feedback has shown that this approach has helped support people to; gain paid employment; volunteer; receive education; manage health effectively; develop own ideas in a collaborative setting; travel independently; benefit from social interactions / friendships and relationships; and physical activity.

<table>
<thead>
<tr>
<th>Person</th>
<th>Before Hendra</th>
<th>After Hendra</th>
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</table>
| 1      | • Lived independently in a flat with support. Did not engage well with this support.  
• Isolated, never went out, flat was kept in poor condition  
• Very depressed, mental health was deteriorating. Everyone concerned about the future but unsure of what more could be done. | • Has completely come out of his shell and his flat  
• Wellbeing and health have improved dramatically  
• Socialises every day in the communal space.  
• Has buddied up with other tenants to go out in the daytime and in the evening  
• Has been helping other tenants learn how to make healthy smoothies |
Parents contacted commissioners after engagement event.
- Social workers very concerned about the move to Hendra due to amount of initial support that would be needed from the Mental Health Team.

Volunteering in a charity shop in Liskeard.
- Has only needed a little support from the provider and has had needed no further interventions from other services

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<td>2</td>
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<tr>
<td></td>
<td>- Lived in very poor conditions in his flat with support. Did not engage well with this support.</td>
</tr>
<tr>
<td></td>
<td>- Tenancy was at risk, lots of intervention from the Landlord</td>
</tr>
<tr>
<td></td>
<td>- Mental and physical Health was very poor and deteriorating.</td>
</tr>
<tr>
<td></td>
<td>- Was very underweight due to poor diet and hygiene. Housing and Operational leads contacted commissioners about Hendra</td>
</tr>
<tr>
<td></td>
<td>- had not had a shower for three years as his flat was so cluttered. Now he is showering twice a week!</td>
</tr>
<tr>
<td></td>
<td>- Socialises every day at the scheme and helps staff with rotas and organising events.</td>
</tr>
<tr>
<td></td>
<td>- Accepting support and keeping his flat tidy. Disposing unwanted food and clutter.</td>
</tr>
<tr>
<td></td>
<td>- Cooking his own food with support and engaging in cookery activities at the scheme.</td>
</tr>
<tr>
<td></td>
<td>- Buddies up and supports others at the scheme by taking them out shopping etc.</td>
</tr>
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</table>

Responses from wide ranging stakeholders on the consultations regarding the provision of external day services (Marks, 2016) were mixed, although common themes were around people wanting more flexible services, which will be a challenge for service providers. When asked about day services, people with learning disabilities and service users said “it’s not important to have our own building. Would like somewhere to meet that has facilities and go from there to other activities” and “It is important to have a base to meet that is dry, warm and has toilets and a café, but do not need to stay there”. People with learning disabilities highlighted participation in diverse activities during the day, evening and weekends, including for example helping people, looking at wildlife, listening to music / watching TV, going out, spending time with friends and walking etc. When asked where people would spend their money through an ‘action’ task, people were willing to pay more for wide ranging factors. The top three from each event were having qualified staff, nice building, and planning for the future/evening activities (event 1); and being involved in the community, doing interesting things and paid work (event 2) (Marks, 2016).
This work raises the needs and aspirations of people with learning disabilities. Further research into the extent of these barriers (e.g. assistive technology and alternative therapies) and facilitators (e.g. housing, tailored services, support, independent living, and community activities) is necessary to help inform future policy and practice. For example, identifying and evaluating the effectiveness of new technologies has the potential to inform services and alleviate some of the barriers experienced by people with learning disabilities.

6.3 Complaints

The Cornwall Council Information Governance team manages safeguarding, governance and complaints. However it is not currently possible to identify complaints made by people with a learning disability or from their families and carers. The Patient Advice and Liaison Service (PALS) provide a liaison service for user of NHS adult community health, mental health and learning disability services to people of all ages. People with a learning disability, their family or carer can contact the trust to raise any comments, concerns, complaints and compliments. A total of 84 complaints from people with a learning disability and/or their carers were received over the last five years, predominantly for access to healthcare, clinical treatment, provision of information and to relative/carer and nursing care (Figure 6.1). Although these have not been analysed in detail for this needs assessment, these themes could be explored further in research with people with a learning disability.

Figure 6.3 Complaints received between 2012 and 2017
7.0 Effective Interventions (a brief review of evidence)

Differences in health status are, to a large extent, avoidable (Emerson et al., 2011, PHE, 2016a). Based on preventative approaches and early childhood inequalities, national and local interventions should encompass three key actions: reducing child poverty; reducing exposure to specific hazards; and building resilience (Emerson, 2015). To find out more about the effectiveness of recent interventions, a brief literature review has been completed. Basic literature searches were conducted in an electronic database known as Pubmed using synonyms for learning disabilities and interventions. Searches were restricted to systematic review articles and a publish date of 2010 (i.e. the date of the last needs assessment).

A total of 325 potential articles were identified. Following screening of title and abstracts, 19 systematic reviews were identified, which highlighted a range of interventions to improve the physical and mental health of people with learning disabilities (The details of these studies can be found in Appendix 1.0). This section aims to provide an overview of included systematic reviews and some of the evidence supporting interventions, which aim to improve health and well-being of people with learning disabilities. Due to timescales and resourcing, this is not meant to be a definitive list of potential interventions, which would require a formal systematic review of reviews, which is outside the scope of this needs assessment.

A number of limitations exist. Due to resource constraints, there was insufficient time to fully extract more detailed information on the quality of systematic reviews or on the participant, intervention and outcome characteristics. Furthermore, it was difficult to identify if differences exist between the UK definition of ‘learning disability’ and the international literature, which uses ‘intellectual disabilities’. Reviews were excluded if reported on dyslexia or people experiencing a brain injury or trauma for example. Please refer to articles for further details on intervention / participation characteristics and outcomes.

Previous sections raised concerns over a growing population of people with learning disabilities and potential impact of challenging behaviour, mental health, unhealthy behaviours, health checks/services and moderate to severe disabilities. Despite the limitations of this literature search, there are wide ranging interventions focusing on these specific factors (Appendix 1.0). These include health checks, lifestyle, carer-led, challenging behaviour, mental health, severe and profound and health services interventions. When considering the evidence, it is important to consider that evidence supporting these interventions appears to be mixed and of low to medium quality.

Health checks for people with a learning disability are effective, but the cost-effectiveness of this approach is yet to be fully tested. Lifestyle interventions resulted in mixed findings, but highlighted the importance of increasing physical activity. There
appears to be some evidence supporting parent training programs, physical activity on challenging behaviour and motor interventions. Further higher quality research is needed, particularly in areas such as behavioural change techniques, physical activity, substance misuse, carer-led, mental health and health services interventions.

Other non-systematic reviews were identified. While they are not as robust as systematic reviews, they provide useful insights into interventions for people with learning disabilities, particularly across areas not adequately covered, which included early years and older adults for example.

There is the potential for developing prenatal, perinatal and neonatal interventions to help alleviate the risk of developing a learning disability. Despite a lack of comprehensive studies across early childhood, it is generally thought that children and families benefit from early intervention programmes (e.g. careful sequencing of learning activities and environmental structure). Thus, it is important to consider the importance of relationships, preschool inclusion and need for future early interventions systems (Guralnick, 2017).

Older adults with learning disabilities are another vulnerable population. A general review of potential interventions showed that the ideal health promotion and disease prevention strategies should be tailored to the individual’s health risks, address primary and secondary disease prevention, and prevent avoidable impairments that cause premature institutionalisation. Domains of interventions should include cognitive, mental and physical health, accommodations, workplace considerations, assistive technology, recreational activities, and nutrition (Carmeli and Imam, 2014). A scoping review further investigates interventions targeting the health of older people with learning disabilities (Heller et al., 2014).

Fitness/exercise interventions resulted in improved balance, strength, and aerobic capacity, in addition to lower blood pressure. Behavioural and psychological outcomes included reduced challenging behaviour, anxiety, hyperactivity, and greater focus and attentiveness. Evidence from multi-component health promotion programs (e.g. Health Matters: The Exercise, Nutrition and Health Education Curriculum for People with Developmental Disabilities) indicated that they can result in positive physical, health behaviour, and psychosocial outcomes. Studies of health screenings found that these screenings generally resulted in more subsequent clinical activities. Other benefits reported included less pain, fewer falls, fewer emergency room visits and greater satisfaction. Other innovative interventions utilised additional support and technology. These demonstrated the important role of sustained support by caregivers, support personnel, and professionals in facilitating positive outcomes of health promotion interventions, as well as showing the benefits of coupling an individualised needs approach exercise program with support (Heller et al., 2014).

The full extent of comorbidities in people with learning disabilities remains yet to be fully explored. Over the past 15 years, there has been increased focus on treating
these complex conditions, including the need to integrate mental and behavioural health treatments into primary care. A recent book chapter highlighted that healthcare must account for multiple domains of quality of life, going beyond yearly physicals and acute care visits, for example, to assess individual’s health care goals and support them in achieving those goals. While integrated healthcare delivery systems can be difficult to find and access for people with learning disabilities, such approaches are more responsive to their comprehensive needs and desires (Williams and Ervin, 2016).

Another review investigated interventions that aim to improve the knowledge and attitudes of the general population towards people with learning disabilities. Despite some methodological limitations, majority of studies reported promising outcomes, particularly those aimed at increasing knowledge of learning disability through education. Interventions delivered at least partly by individuals with intellectual disabilities, and educational interventions appear to hold the most promise (Seewooruttun and Scior, 2014).

An evidence-based initiative shows that are potentially five ways people could improve their well-being, namely the following; 1. Connect with people; 2. Be active; 3. Notice things around you; 4. Keep learning; and 5. Give to others. While participants in the study found the group useful and increased mindfulness practice, there is no evidence that running a Five Ways to Well-being group with people with learning disabilities (not a clinical group with mental concerns) will improve their well-being (Mahoney-Davies et al., 2016).

Pharmacists may also have a role to play. There is some limited evidence supporting the role of pharmacists in improving the quality of the medication use process, in collaboration with other healthcare professionals, carers and patients with a learning disability. The narrative review makes it difficult to determine the potential impact pharmacists may have (O’Dwyer et al., 2015).
8.0 Recommendations

This needs assessment update has identified a number of recommendations that should be incorporated into the development of future strategies and service developments. It should also be noted that many of these recommendations focus on health care, which is a reflection of the accessibility of the data.

<table>
<thead>
<tr>
<th>Needs assessment recommendations</th>
<th>Lead organisation / service</th>
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<tbody>
<tr>
<td>1. Stakeholders to review and incorporate national guidance and policies described in the policy update (Section 3.0) in commissioning and service delivery. In particular the National Service Model: mainstream NHS services (NHS England, 2015b), PHE guidance (PHE, 2017a) and NICE guidance (NICE, 2017).</td>
<td>All</td>
</tr>
<tr>
<td>2. It is recommended that the findings of this needs assessment inform the strategic planning cycle in commissioning organisations. There is a need for increased collaboration between key stakeholders and planning to inform future needs assessment updates and development of future strategies</td>
<td>Children, Families and Adults, Cornwall Council; Kernow Clinical Commissioning Group; and Cornwall Partnership Foundation Trust</td>
</tr>
<tr>
<td>3. Cornwall Council holds diverse information on children and adults (e.g. education, employment, finance, complaints, safeguarding and social care etc.) with learning disabilities, but data is not readily available. It is recommended that a standard template is developed and an annual report produced for the needs assessment process.</td>
<td>Performance management data, Children, Families and Adults, Cornwall Council</td>
</tr>
<tr>
<td>4. Learning Disability Partnership Board to take ownership of this needs assessment, promote more collaborative working and review progress made in implementing these recommendations. This should be delivered alongside the monitoring and reporting of how local services are performing against the recommendations made by national policy (Emerson et al., 2011) and (Heslop et al., 2013).</td>
<td>Cornwall Council &amp; Healthwatch</td>
</tr>
<tr>
<td>5. In line with the previous needs assessment, this update highlights the continual trend in the increasing number of people with learning disabilities. Commissioners and service providers should ensure that plans are in place to meet the needs of:</td>
<td>Children, Families and Adults, Cornwall Council</td>
</tr>
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- Increasing numbers of children and adults with learning disabilities, particularly those with more severe learning disability.
- Those coming through transition.
- Increasing numbers of older adults with learning disabilities.
- Increased number of carers becoming too old and frail to continue with care.

6. This needs assessment highlighted the need for additional research to fill the information gap and inform future health promotion and protection strategies across Cornwall. These include:
   a) Wider determinants of health (e.g. housing, employment, education, transport and unhealthy lifestyle characteristics such as substance misuse). Including factors impacting quality of life, quality of care and support, loneliness, social exclusion and isolation, lack of control and feelings of respect, feeling empowered and having self-determination to play an active role in a community;
   b) The extent, impact and benefits of personal budgets, alongside potential challenges faced by people living independently (e.g. levels of deprivation, crime and discrimination) and the impact this has on population sub-groups;
   c) Parents with a learning disability and its impact on their children;
   d) Co-morbid conditions (i.e. more than one health problem) among people with a learning disability;
   e) Experiences and perceptions of health care systems at the population level (e.g. quality of health checks, immunisation and screening);
   f) The appropriate use of sign posting;
   g) The impact and experiences of in county placements;
   h) Accessing dental and sensory impairment services;
   i) The challenges faced by an aging learning disability population and their carers, as well as the impact of age specific problems such as falls, sensory impairments and profound learning disabilities;
   j) Extent and type of complaints made, themes and actions taken;
   k) Experiences and perceptions of people transitioning from childhood into adulthood; and

Public Health, Cornwall Council
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<tr>
<td><strong>1.</strong> Community voice – understanding the views, experience and perceptions of stakeholders.</td>
<td>Cornwall Council, Kernow Clinical Commissioning Group and Cornwall Partnership Foundation Trust</td>
</tr>
<tr>
<td><strong>7.</strong> Improvements should be made in the routine collection of service data across all equality groups, including learning disabilities, in order to better monitor outcomes for groups with protected characteristics and fulfil the public sector duty of the Equality Act.</td>
<td>Cornwall Council, Kernow Clinical Commissioning Group and Cornwall Partnership Foundation Trust</td>
</tr>
<tr>
<td><strong>8.</strong> There was no information available on the BME population with learning disabilities, which is a requirement of the Equality Act 2010. Service providers to ensure that there are monitoring and reporting mechanisms in place to feed into the needs assessment process. This may be covered by the following recommendation, but requires further investigation.</td>
<td>Cornwall Council, Kernow Clinical Commissioning Group and Cornwall Partnership Foundation Trust</td>
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<tr>
<td><strong>9.</strong> Routine monitoring and reporting of key outcome measures such as those highlighted in the Health Equality Framework (HEF) or similar mechanism is required across health and social care services. This will help improve our understanding of the health needs of people with learning disabilities and assess the impact of specialist services. Consistently sharing reports with Public Health would significantly improve the health needs assessment process.</td>
<td>Cornwall Council, Kernow Clinical Commissioning Group and Cornwall Partnership Foundation Trust</td>
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<tr>
<td><strong>10.</strong> Develop systems that enable the identification of complaints being made by people with learning disabilities and their carers, which will help identify any potential trends. Develop mechanisms to share with Public Health to improve the needs assessment process.</td>
<td>Children, Families and Adults, Cornwall Council, Kernow Clinical Commissioning Group and Cornwall Partnership Foundation Trust (including PALs)</td>
</tr>
<tr>
<td><strong>11.</strong> To audit, monitor and report on the uptake of learning disability health checks and health action plans via the health check framework when established. This should include an investigation into whether NHS Digital can accurately monitor the number of health checks being completed by GP practices.</td>
<td>Kernow Clinical Commissioning Group</td>
</tr>
<tr>
<td><strong>12.</strong> Health promotion activities to consider the development of specialist programmes appropriate for people with learning disabilities who are under and overweight increasing physical activity, and improving uptake of immunisations and cancer screening.</td>
<td>Health Promotion, Cornwall Council</td>
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<tr>
<td>To understand the reach and effectiveness of interventions, health promotion should put in measures to enable the effective evaluation of learning disability programmes.</td>
<td>Increase uptake of direct payments/personal budgets and make appropriate plans for future housing, extra care and support needs for people with learning disabilities which promote independent living, healthy ageing and protect vulnerable adults living in the community.</td>
</tr>
<tr>
<td>Health Promotion, Cornwall Council</td>
<td>Children, Families and Adults, Cornwall Council</td>
</tr>
<tr>
<td>14.</td>
<td>15. The use of new technologies has the potential to help support people with learning disabilities. Opportunities for research and innovation should be explored to identify the most effective technologies. Including support in the use of better communication systems in health and social care services to improve some of the communication difficulties that may exacerbate challenging behaviour in people with learning disabilities.</td>
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<tr>
<td>15.</td>
<td>16. Improved training and professional development;</td>
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<tr>
<td>The introduction of universal credit presents particular risks to people with a learning disability (e.g. opening bank account). These risks should be reviewed and mitigated against to reduce impact on this vulnerable group.</td>
<td>Provision of reasonable adjustments, including health checks for example;</td>
</tr>
<tr>
<td>Children, Families and Adults, Cornwall Council Shaping Our future (Integrated Care)</td>
<td>Maternity and social services to ensure adequate awareness of child welfare and supporting parents with a Learning Disability;</td>
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<tr>
<td>16.</td>
<td>16. Improved training and professional development;</td>
</tr>
<tr>
<td>The introduction of universal credit presents particular risks to people with a learning disability (e.g. opening bank account). These risks should be reviewed and mitigated against to reduce impact on this vulnerable group.</td>
<td>Consider role of the learning disability Acute liaison nurses/Screening liaison nurses and expertise in supporting development of integrated care teams and training future workforce;</td>
</tr>
<tr>
<td>Children, Families and Adults, Cornwall Council Shaping Our future (Integrated Care)</td>
<td>Improve staff confidence in supporting people with learning disabilities during palliative and end of life care and ensure reasonable adjustments are considered. Also, need to consider adopting the ReSPECT framework (ReSPECT, 2017) for advance care planning;</td>
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<tr>
<td>16.</td>
<td>16. Improved training and professional development;</td>
</tr>
<tr>
<td>The introduction of universal credit presents particular risks to people with a learning disability (e.g. opening bank account). These risks should be reviewed and mitigated against to reduce impact on this vulnerable group.</td>
<td>Raising awareness to help ensure that early years risk factors for children with Learning Disabilities</td>
</tr>
<tr>
<td>Children, Families and Adults and Public Health and Wellbeing, Cornwall Council, Kernow Clinical Commissioning Group and Cornwall Partnership Foundation Trust Shaping Our Future (Integrated Care)</td>
<td>NHS Community Education Provider Network</td>
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- (e.g. breastfeeding, parenting, exposure to violence) are adequately addressed to reduce health inequalities;
  - f. Ensure adequate education and support is available for people with learning disability to enjoy healthy sexual relationships.

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<tr>
<td>17. Address delays in access to treatment, diagnosis and needs of people with learning disability in treatment pathways, particularly circulatory disease, respiratory disease and cancer to reduce premature death.</td>
<td>Royal Cornwall Hospital Trust, Shaping Our Future Pathways Board,</td>
</tr>
<tr>
<td>18. Work with employment agencies and employers to ensure that people with learning disability have access to appropriate education, training and employment opportunities (including supported employment opportunities).</td>
<td>Employability Cornwall, Cornwall Council Local Economic Partnership</td>
</tr>
<tr>
<td>20. The needs of parents/carers of people with learning disability should be proactively assessed and plans put in place that considers their concerns about the lack of planning for the future. This should be integrated into the development of the Carers Strategy (Cornwall Council, 2017c).</td>
<td>Cornwall Council (Carers Strategy) Kernow Clinical Commissioning Group (primary care)</td>
</tr>
<tr>
<td>21. Simplify the application process for concessionary bus fares for people with a learning disability, and review other issues such as making bus timetabling etc. more accessible.</td>
<td>Transportation Service, Cornwall Council</td>
</tr>
<tr>
<td>22. Review locality team support for people with learning disability is adequate and appropriate for current and future projected population.</td>
<td>Economic Development &amp; Culture, Community Network Areas, Cornwall Council</td>
</tr>
<tr>
<td>23. Review policy and service delivery to prevent the over medicalisation of people with learning disabilities.</td>
<td>Kernow Clinical Commissioning Group and Cornwall Partnership Foundation Trust</td>
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## Summary of interventions reported by systematic reviews and meta analyses

<table>
<thead>
<tr>
<th>Category</th>
<th>Author, year, location of corresponding author</th>
<th>No. of included studies, No. from the UK</th>
<th>Quality of included studies</th>
<th>Population</th>
<th>No. of RCT included</th>
<th>Type of interventions included</th>
<th>Outcome/s of interest</th>
<th>Summary of main finding/s</th>
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<tbody>
<tr>
<td>Health checks</td>
<td>Robertson et al. (2014), UK</td>
<td>45 &amp; 43 from the UK (19 from England)</td>
<td>Not assessed. All studies considered regardless of quality</td>
<td>All age groups</td>
<td>None</td>
<td>Health checks</td>
<td>Health conditions, resultant health actions, health gains, perceptions, impact on social care staff &amp; healthcare, gaps / barriers &amp; cost</td>
<td>Health checks are effective; in identifying a wide range of previously unidentified conditions (minor through to serious &amp; 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</td>
</tr>
<tr>
<td>Lifestyle</td>
<td>Brooker et al. (2015), only abstract available</td>
<td>6 &amp; not reported</td>
<td>Poor</td>
<td>-</td>
<td>-</td>
<td>health education or health promotion programs with PA, nutrition, and weight loss components</td>
<td>Improved involvement in physical activity</td>
<td>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</td>
</tr>
<tr>
<td>Category</td>
<td>Author, year, location of corresponding author</td>
<td>No. of included studies, No. from the UK</td>
<td>Quality of included studies</td>
<td>Population</td>
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<td>Outcome/s of interest</td>
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<tr>
<td>Willems et al. (2017), Netherlands</td>
<td>45 &amp; not reported</td>
<td>Low quality, but 10/13 RCT studies were of medium to high quality</td>
<td>All age groups</td>
<td>13</td>
<td>Behavioural change techniques (BCT)</td>
<td>To improve lifestyle interventions for physical activity, nutrition or both</td>
<td>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</td>
<td></td>
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<tr>
<td>Harris et al. (2015), UK</td>
<td>6 &amp; 0 UK</td>
<td>5/6 studies were high quality and 1 was of moderate quality</td>
<td>Young adults (16-24 years)</td>
<td>6</td>
<td>Physical activity interventions</td>
<td>Body weight and composition</td>
<td>There was no significant effect of physical activity interventions on body weight or body composition outcomes</td>
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</tbody>
</table>
## Summary of interventions reported by systematic reviews and meta analyses

<table>
<thead>
<tr>
<th>Category</th>
<th>Author, year, location of corresponding author</th>
<th>No. of included studies, No. from the UK</th>
<th>Quality of included studies</th>
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<th>Outcome/s of interest</th>
<th>Summary of main finding/s</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Maïano et al. (2014), Canada</td>
<td>9 &amp; 0 UK</td>
<td>Weak to moderate</td>
<td>7-22-year-olds with mild-moderate learning disability</td>
<td>Not clearly reported</td>
<td>Interventions designed to promote changes in body weight and composition e.g. dieting, physical activity, health promotion, and/or cognitive-behavioural</td>
<td>Changes in body weight and composition (weight, body mass index, body fat, waist circumference)</td>
<td>Despite the limitations of included studies, intervention outcomes suggest successful changes in weight, body mass index and fat mass</td>
</tr>
<tr>
<td></td>
<td>Jackson et al. (2015), UK</td>
<td>1 &amp; not reported</td>
<td>Unclear risk of bias</td>
<td>People aged 12+ with a learning disability and epilepsy</td>
<td>1</td>
<td>Non-pharmacological. Included but not limited to surgical procedures, diets, psychological, yoga, acupuncture and relaxation therapy</td>
<td>Retention on treatment, freedom from seizures, reduction in seizure frequency and severity. Secondary outcomes included behavioural, cognitive outcomes, adverse effects, and quality of life</td>
<td>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 seizure and behavioural outcomes.</td>
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<td>Summary of interventions reported by systematic reviews and meta analyses</td>
<td>Spanos et al. (2013), UK</td>
<td>22 &amp; 4 UK</td>
<td>Not clearly reported but appears to be low quality</td>
<td>Adults aged &gt;18</td>
<td>None, Quasi-exp. design</td>
<td>Non-surgical or pharmacological interventions</td>
<td>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)</td>
<td>Current data indicate weight management interventions in those with ID 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.</td>
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<td>Kerr et al. (2013), UK</td>
<td>9 &amp; 6 UK</td>
<td>Poor to moderate</td>
<td>Adults</td>
<td>1</td>
<td>Tobacco and/or alcohol interventions such as information / advice, education, group support, other psychological / pharmacological interventions</td>
<td>Reduced bio markers for smoking and alcohol use, quality of life, knowledge and attitudes</td>
<td>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</td>
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<tr>
<td>Carer-led</td>
<td>Hithersay et al. (2014), UK</td>
<td>24 &amp; 4 UK</td>
<td>Small scale, with short follow up, studies and varying levels of quality. Efficacy could not be assessed</td>
<td>Adult and child participants older than 2 years</td>
<td>14</td>
<td>Carer-led health interventions; health check questionnaire, health promotion, symptom monitoring &amp; management, mental health &amp; screening</td>
<td>Physical and mental health</td>
<td>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</td>
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<tr>
<td>Challenging behaviour</td>
<td>Sheehan and Hassiotis (2017), UK</td>
<td>21 &amp; 5 European</td>
<td>Studies lacked in volume, quality and scope</td>
<td>Adults</td>
<td>1 (reported in two studies)</td>
<td>The reduction or discontinuation of antipsychotic medication</td>
<td>Proportion of participants achieving dose reduction or discontinuation without drop-out or reinstatement of the antipsychotic. Secondary outcomes included behavioural and health outcomes</td>
<td>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</td>
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<td></td>
<td>Leong et al. (2015), Australia</td>
<td>17 &amp; not reported</td>
<td>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</td>
<td>All age groups and mainly challenging behaviours (11 studies)</td>
<td>0</td>
<td>Sensory integration therapy (SIT)</td>
<td>Sensory integration and perceptual-motor measures; short and long term functional measures</td>
<td>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</td>
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<td>Kok et al. (2016), Netherlands</td>
<td>11 (reported in 12 reports) &amp;</td>
<td>Low or unclear risk of bias. Used JHAD scale for inclusion.</td>
<td>Children with mild to borderline learning disability and a psychiatric disorder</td>
<td>11 though not clearly reported</td>
<td>Parent training programmes, social competence training and cognitive behaviour therapy</td>
<td>Challenging behaviour</td>
<td>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, $I^2$ 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</td>
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<td>Ogg-Groenendaal et al. (2014), The Netherlands</td>
<td>20 &amp; not reported</td>
<td>Mostly low quality</td>
<td>All ages with challenging behaviour</td>
<td>Not reported</td>
<td>Physical activity &amp; exercise</td>
<td>Change in challenging behaviour</td>
<td>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.</td>
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<td>Mental health</td>
<td>Koslowski et al. (2016), Germany</td>
<td>12 (10 in meta-analyses) &amp; not reported</td>
<td>Moderate and high heterogeneity</td>
<td>Adults with mild to moderate learning disability</td>
<td>12</td>
<td>Psychotherapy, biological or system level</td>
<td>Behavioural problems, depressive / anxiety symptoms, quality of life and functioning</td>
<td>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.</td>
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<td>Vereenooghe and Langdon (2013), UK</td>
<td>22 &amp; 12 UK</td>
<td>Reported methodological issues</td>
<td>Aged &gt;5 years</td>
<td>0</td>
<td>Psychological principles and techniques</td>
<td>Prevention or treatment of emotional, behavioural or mental health problems</td>
<td>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</td>
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<td>Severe or profound learning disability</td>
<td>Houwen et al. (2014), Netherlands</td>
<td>45 (46 articles) &amp; not reports</td>
<td>Not clearly reported</td>
<td>All ages with severe or profound learning disability (i.e. IQ &lt; 35, mental age)</td>
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<td>Motor interventions</td>
<td>Improve motor, cognitive, and/or social outcomes</td>
<td>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</td>
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<td>Health services</td>
<td>Balogh et al. (2016), Canada</td>
<td>7 &amp; not reported</td>
<td>Assessed risk of bias, which ranged from low to high risk. But most had a low risk of bias despite small sample sizes</td>
<td>Adults</td>
<td>7</td>
<td>Developing and implementing evidence-based guidelines and protocols, supporting guidelines or protocols through health provider, self-management and reorganising health services</td>
<td>Behavioural, mental and physical health problems, and health system use. Secondary outcomes included psychological health and quality of life.</td>
<td>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</td>
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<td>Robertson et al. (2017), UK</td>
<td>35 &amp; 17 UK</td>
<td>Low</td>
<td>All age groups with a learning disability and epilepsy</td>
<td>0</td>
<td>Interventions aiming to improve knowledge or practice in relation to service responses</td>
<td>Current knowledge or practice in relation to service responses and factors associated with outcomes for people with intellectual disabilities and epilepsy</td>
<td>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</td>
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<td>Parenting</td>
<td>Wilson et al. (2014), UK</td>
<td>7 &amp; not reported</td>
<td>Low</td>
<td>Adults with mild/moderate learning disability</td>
<td>1</td>
<td>Interventions for parents with learning disabilities</td>
<td>Not restricted by outcome as long as it was quantitatively assessed</td>
<td>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</td>
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