

Learning Disabilities: Data Briefing

Introduction

The purpose of this report is to describe the needs of people in East Sussex who have learning disabilities, identifying the health inequalities experienced by this group compared to the general population. This report will be used to inform local strategy around support for people with learning disabilities.

This data briefing focuses on people of all ages with learning disabilities in East Sussex. Where possible, all those with learning disabilities are included. However, there are some people, particularly with mild learning disabilities who are not known to GPs or local authorities and obtaining their views, experiences and quantifying needs are much more difficult. This means there is an incidental bias towards addressing the needs of those known to statutory services in East Sussex. The report also captures some information around those with Autistic Spectrum Disorders (ASDs). This briefing was requested by the lead for Transforming Care for all three CCGs in East Sussex.

This briefing analyses the evidence available for people with learning disabilities within East Sussex County Council and health partners, combined with nationally published statistics and research materials. The evidence base looks at current literature and East Sussex intelligence about the prevalence and trends in special educational needs and/or disability.

There are a number of potential limitations to the data presented in this briefing. Extrapolation from national prevalence estimates only take age and gender into account and do not include other factors particular to East Sussex. Furthermore, local data systems, methods of information recording, reasons for data collection and definitions of learning disability differ between different services and departments, and this needs to be considered when describing the data.

The data recording also differs depending on who is recording the information. For example the primary need recorded for someone may be different if recorded by a mental health social worker than a learning disability social worker, or a GP. However, despite these limitations, by pulling all the evidence together we are able to give the most comprehensive picture possible of the needs of people with learning disabilities in East Sussex, and how these needs might be met.

Defining Learning Disability

Learning disability refers to a significant general impairment in intellectual functioning that is acquired during childhood¹ and encompasses a range of conditions and levels of severity which may be accompanied by physical, psychological and psychiatric illness and disability.² Valuing People³, the 2001 White Paper on the health and social care of people with learning disabilities, defines learning disability as the presence of:

"A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development"

Internationally three criteria are regarded as requiring to be met before a learning disability can be identified or diagnosed⁴:

- intellectual impairment (IQ)
- social or adaptive dysfunction combined with IQ
- early onset

A learning disability affects the way a person understands information and how they communicate, meaning they may have difficulty: understanding new or complex information; learning new skills and coping independently. Associated impact on an individual's educational, social, economic and life choices, with difficulties with social communication (linked to increased challenging behaviour) are central to the reduction of access to education, employment and social integration.^{5,6} However, in UK education services, there are four recognised Special Educational Needs (SEN) codes for learning difficulty:

1. **Specific learning difficulty (SpLD):** an umbrella term for those displaying difficulties across their learning. Specific Learning Difficulties include: Dyslexia; dyscalculia and dyspraxia⁷.
2. **Moderate learning difficulty (MLD):** Attainment below expected levels in all or most areas of the curriculum, despite appropriate interventions. Those with MLD may also have associated speech and language delay, low self-esteem, poor concentration and under-developed social skills.³⁷
3. **Severe learning difficulty (SLD):** significant intellectual or cognitive impairments with a major effect on ability to participate in the curriculum without support in all areas. There may also be associated difficulties with mobility, co-ordination, communication and self-help skills.³⁷

4. **Profound and multiple learning difficulty (PMLD):** more than one disability, with the most significant being a learning disability.⁸ Severe and complex learning needs and a high level of adult support required for both learning and personal needs. Communication is mostly by gestures, eye-pointing, symbols or simple language.³⁷

In the UK it is widely accepted that the terms learning “difficulty” and learning “disability” refer to the same population when looked at in the context of health and social care for adults.⁹ Other terms that are used to describe an individual’s situation include complex needs or high support needs. This report focusses on people of all ages with learning disabilities and does not look in detail at children with specific learning difficulties (SpLD).

A minority of people with learning disabilities exhibit challenging behaviour. They can present a risk to themselves, and others such as their families and the public. Challenging behaviour can include self harm, violence and aggression.¹⁰ The number of people with learning disabilities and/or autism who may also display behaviour that challenges is steadily increasing.

Due to advances in healthcare, those with particular medical conditions who may have historically died in childhood are now surviving and living with those conditions. Life expectancy for people with learning disabilities is also increasing¹¹. As adults live longer they are experiencing more complex health and social care needs¹². The number of people with learning disabilities known to GPs has gone up every year for the last six years.¹³

Learning disability does not cover adults or young people who have acquired brain damage or those with organic mental health problems such as dementia.

The term autism describes a lifelong disorder where there are: “qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours”.¹⁴ ASD is a collective term that includes: Autism; atypical autism; and Asperger’s syndrome.

Causal Factors

A learning disability happens when a person's brain development is affected, either before they are born, during their birth or in early childhood. Sometimes there is no known cause for a learning disability but several factors can affect brain development:

- the mother becoming ill in pregnancy
- problems during the birth that stop enough oxygen getting to the brain
- the unborn baby developing certain genes
- the parents passing certain genes to the unborn baby that make having a learning disability more likely (known as inherited learning disability)
- illnesses, injury or environmental conditions, for example, meningitis, brain injury or children being deprived of attention to their basic needs - undernourished, neglected or physically abused¹⁵.

Some genetic or ‘congenital’ conditions, including Down’s syndrome, Cerebral Palsy or Fragile X syndrome are associated with having a learning disability. Everyone with Down’s syndrome, for example, has some kind of learning disability, and so do many people with cerebral palsy. People with autism may also have learning disabilities, and around 30% of people with epilepsy have a learning disability. Sometimes other factors can affect a baby before it is born, such as drug or alcohol use by the mother.^{16, 17}

A PICTURE OF LEARNING DISABILITY

Commissioning for learning disabled populations in East Sussex

Within East Sussex, the County Council has responsibility for the commissioning and care management of East Sussex residents, but not for individuals who are funded and placed in East Sussex from other areas outside of the county. East Sussex does have responsibility for safeguarding within the county. Support is based on eligible need as opposed to clinical diagnosis, meaning services vary according to individual need, not just in relation to the severity of their learning disability but on a range of related factors, for example levels of family support.

Clinical Commissioning Groups (CCGs) have responsibility for the health needs of individuals registered with a member GP regardless of who funds their care. This doesn’t always involve responsibility for case management, placement or funding arrangements which rest with the placing authority. There is also likely to be a group of people with mild learning disabilities and no additional needs who are not eligible for, or do not require additional services. Research shows only a minority of people with less severe learning disabilities are known to services.¹⁸

Transforming Care

The Transforming Care Programme is a coordinated, national response to the Panorama investigation (2011) into Winterbourne Hospital, near Bristol, which exposed the abuse suffered by people with learning disabilities and challenging behaviour.

The national plan, Building the Right Support, has been developed jointly by NHS England, the LGA and ADASS. It is supported by a new Service Model for commissioners across health and care which defines what good services should look like and gives commissioners a clear framework to develop more community services for people with learning disabilities and/ or autism who display behaviour that challenges, including those with a mental health condition, and to reduce the number of inpatient facilities.

The plan builds on other transforming care work to strengthen individuals' rights; roll out care and treatment reviews across England, to reduce unnecessary hospital admissions and lengthy hospital stays; and test a new competency framework for staff, to ensure we have the right skills in the right place. The Transforming Care programme is focusing on addressing long-standing issues to ensure sustainable change that will see:

- More choice for people and their families, and more say in their care;
- Providing more care in the community, with personalised support provided by multi-disciplinary health and care teams ;
- More innovative services to give people a range of care options, with personal budgets, so that care meets individuals' needs;
- Providing early more intensive support for those who need it, so that people can stay in the community, close to home;
- But for those that do need in-patient care, ensuring it is only for as long as they need it.

Prevalence

In England approximately 1.2 million people have learning disabilities (including all levels of need). This equates to approximately 2% of the population.¹⁹ 210,000 (3–4 in 1,000 people) are estimated to have severe or profound Learning disability,²⁰ around 25% of whom are under 16 years of age. Evidence from 2015/16 QOF registers suggest that primary care will have reported lower numbers than predicted, with 0.5% of people (all ages) on GP registers having recognised learning disability.²¹

East Sussex population

There is currently a resident population in East Sussex of approximately 544,000 people.²² Table 1 shows estimated populations by district, borough and CCG.

Table 1: East Sussex Population –Mid year 2015

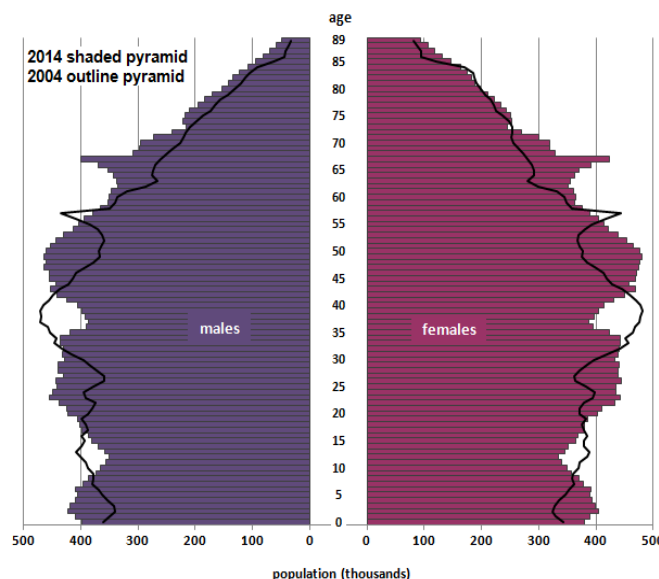
	Resident population	males	females
EAST SUSSEX	544,064	262,957	281,107
Eastbourne	102,465	49,483	52,982
Hastings	91,497	44,720	46,777
Lewes	100,693	48,890	51,803
Rother	92,908	44,453	48,455
Wealden	156,501	75,411	81,090
EHS CCG	188,088	90,357	97,731
H&R CCG	184,405	89,173	95,232
HWLH CCG	171,571	83,427	88,144

Source: ONS, 2015

Age

In mid-2014, the population of the UK consisted of 31,793,600 males (49.2%) and 32,803,100 females (50.8%) (Figure 1). The median age of the population is 40 years, the highest ever. The number of males aged 85 and over has increased by 61.8% since mid-2004 compared to an increase of 25.9% for females.

Figure 1: Age Structure of the UK, mid 2014



Source: ONS mid year estimates 2014

The faster improvement in male mortality is largely driven by changes seen in tobacco smoking and advances in health treatments for circulatory illnesses.

In East Sussex in 2014 children and young people under 18 represented nearly 20% of the population, slightly lower than regionally and nationally (21%), and representing a 0.3% decrease since 2004. Conversely, there have been increases in this age group regionally (6%) and nationally (4%).²³

The working age population 16-64, accounts for around 58% of the total county's population, which is also lower than the national and regional averages of about 63% and 62% respectively. Over the last decade, the working-age population (aged 16-64) grew by 5%, to 314,300, compared to 6% regionally and nationally.

The population aged 65+ (133,100) is relatively higher in East Sussex than nationally and regionally, (25% of the total population in 2014, compared to 18% nationally and 19% regionally). In particular, the proportion aged 75 and over is almost 12%, compared to 9% regionally and 8% nationally. East Sussex ranks second highest of all 27 counties in England based on percentage of the population aged 75+ after Dorset²⁴.

Nationally extrapolated Prevalence estimates

When national prevalence rates²⁵ are applied to local population structures, the estimated numbers with learning disabilities (LD) (including all levels of need) in East Sussex are approximately 10,800 people, broken down as follows (Table 2):

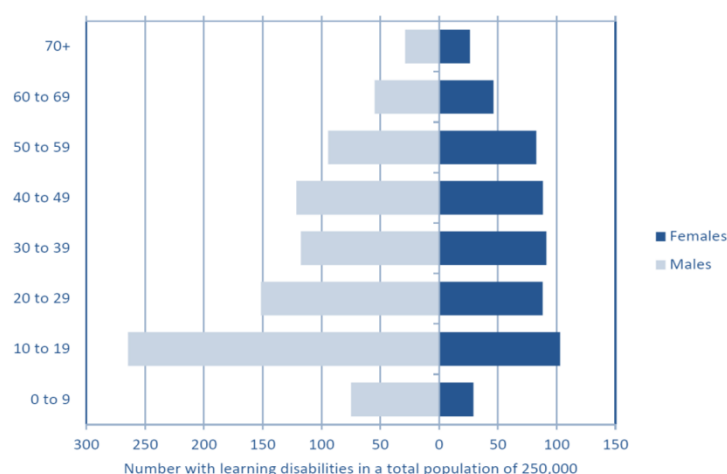
Table 2: Estimated prevalence of learning disability by area and CCG

	People with LD (2%)	People with severe/profound LD (0.35%)
EAST SUSSEX	10,800	1,890
Eastbourne	2,030	355
Hastings	1,820	320
Lewes	2,000	350
Rother	1,840	320
Wealden	3,100	540
EHS CCG	3,800	665
H&R CCG	3,700	645
HWLH CCG	3,350	585

In East Sussex this would equate to 6,290 individuals aged 18-64 with a learning disability (all levels of need).

Estimations of a national age profile of people with learning disabilities²⁶ shows that in a population of 250,000 there is an estimated rate of people with learning disabilities of 5.5 per 1,000, based on information taken from learning disability registers.

Figure 2: Estimates number of people with learning disabilities in a total population of 250,000 (based on



the 2011 national population profile)

Source: Emerson et al, 2013

There are significantly higher estimates of males aged between 10 and 19 with learning disabilities than any other age group, which may reflect increased survival rates among more severely disabled children. Above the age of 49 years, the estimated numbers of people with learning disabilities in the population start to decline (figure 2), mainly due to reduced life expectancy. Low estimated numbers for the youngest age group reflects incomplete recognition of mild to moderate learning disabilities in pre-school children.

ASD

There are around 700,000 people in the UK living with autism, more than one in 100.²⁷ This estimated prevalence of 1.1% suggests approximately:

- 1,600 adults with autism in EHS CCG
- 1,580 adults with autism in H&R CCG
- 1,450 adults with autism in HWLH CCG²⁸

The British Association for Child and Community Health (BACCH) created a calculator of expected service demands for certain clinical conditions including ASD based on a local areas child population and birth rate.²⁹ The prevalence of ASD amongst children in the UK is 1.57%³⁰ (including previously undiagnosed cases), with an incidence (expected new cases) of 81 per year, based on our 0-19 year population of 117,329 people. In total within the 0-19 year population of East Sussex we would expect approximately 1,840 children and young people to have Autism Spectrum Disorder. The tool also calculates 245 expected appointments with community child health services for ASD each year.

Table 3 shows estimated prevalence and incidence of ASD in East Sussex with the greatest expected incidence in Wealden and EHS CCG. CCG projections

suggest a slightly higher total prevalence for East Sussex than ESCC projections as the former is based on ward level data aggregated into CCG area, while the latter is based on district level data. These figures indicate a projected fall in actual numbers of 0-19 year olds with ASD, with more significant decreases expected in Eastbourne and Rother.

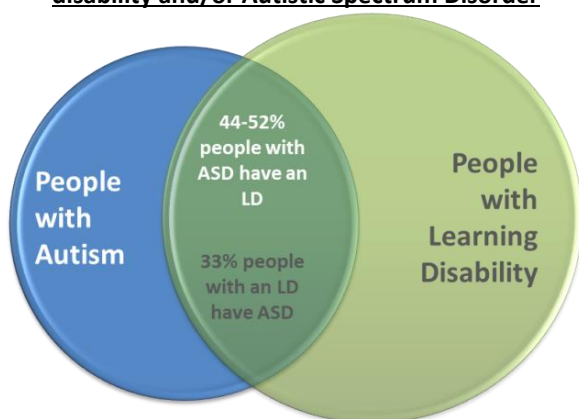
Table 3: Estimated prevalence of ASD, 0-19 year olds

	Estimated Prevalence (1.57%)	Estimated incidence	Expected community child health appointments per year	Estimated future prevalence in 2021
East Sussex	1,840	80	245	1,785
Eastbourne	350	15	50	335
Hastings	340	15	50	325
Lewes	340	15	40	340
Rother	280	10	35	265
Wealden	530	20	65	525
EHS CCG	615	30	90	620
H&R CCG	620	30	85	615
HWLH CCG	610	25	70	580

Source: BACCH Prospectus Calculator Tool, ONS 2014 mid-year estimates, ESCC dwelling led population estimates, CCG population projections

It is estimated that between 44% and 52% of autistic people may have a learning disability³¹, and around a third of people with a learning disability may also be autistic³² (Figure 3), equating to between approximately 3,200 and 3,500 people in East Sussex with both autism and a learning disability.

Figure 3: Estimated population with a learning disability and/or Autistic Spectrum Disorder



However, the National Autistic Society states that it's not possible give an accurate estimate. This is because some very able people with ASD may never come to the attention of services as having special needs because they have learned strategies to overcome any difficulties with communication and social interaction, while others may be able intellectually, but need

support because the degree of social interaction impairment hampers their chances of achieving independence.³³

GP Practice Data

In 2014/2015, there were 2,690 (0.49 per 1,000) patients with learning disabilities (all ages) known to GPs in East Sussex, significantly higher than nationally (0.44) and the second highest area in the South East region behind Isle of Wight (0.66)³⁴.

Table 4 outlines how this breaks down in terms of GP registers for each CCG in East Sussex. According to those recorded on GP registers, there is a greater prevalence of learning disability in Hastings & Rother CCG compared to Eastbourne, Hailsham and Seaford and High Weald Lewes Havens.

Table 4: Numbers on GP Learning Disability Registers, 2014/15

	Full list size 2014/15	Estimated list size 18+	Learning Disability: on register all ages	Learning/Disability prevalence rate
EHS CCG	190,780	155,434	855	0.45
H&R CCG	185,204	150,265	1,078	0.58
HWLH CCG	167,974	134,321	754	0.45

Source: HSCIC, GPES and CQRS database, 2015

In East Sussex as at 12th September 2016 there were 1,000 care home beds (without nursing) for people with learning disability or ASD across 107 locations within East Sussex. The majority of care home beds can be found in Wealden (310), while Hastings has the greatest number of care home services (33) (Table 5).

Table 5: Numbers of care home services and beds for people with an LD or ASD in East Sussex, 12th September 2016

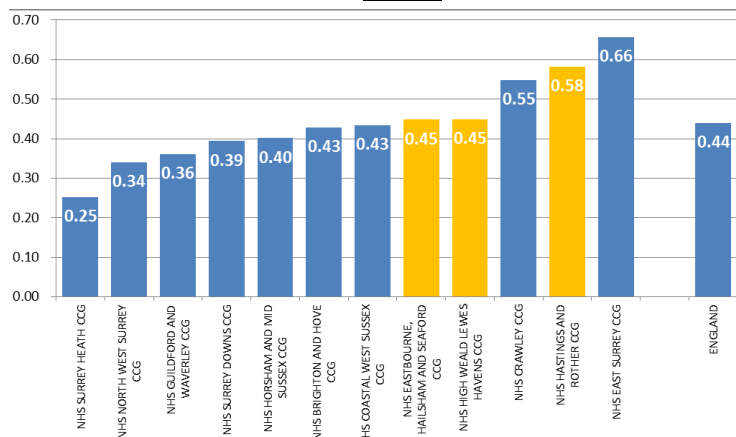
	Number of Locations	Care Home Beds
EAST SUSSEX	107	1,000
Eastbourne	14	108
Hastings	33	214
Lewes	12	100
Rother	25	268
Wealden	23	310

Source: CQC database as at 12 September 2016

It is not possible to break this down into 'number of beds in use' at any point in time, and it should be noted that a location can have more than one service type and more than one service user band.

Within the Surrey and Sussex area team, Hastings and Rother CCG have the second highest prevalence of learning disabilities behind East Surrey CCG (Figure 4).

Figure 4: Practice prevalence of learning disabilities by CCG



Source: QOF 2014/15

Prevalence in Early years

In very early childhood, only severe learning disabilities are likely to be apparent.³⁵ National evidence suggests 0.39% of girls and 0.60% of boys have a primary special educational need of severe or profound multiple learning difficulties (approximately equivalent to severe learning disabilities), so research suggests the prevalence of learning disabilities at age two years and below is 0.39% for girls and 0.60% for boys rising in incremental steps each year to the higher rates of 2.46% of girls and 4.01% of boys identified with learning disability SEN at age five.³⁶

In East Sussex, this would mean that we would expect approximately 18 boys and 11 girls aged under 2 years to have severe learning disabilities, rising to 37 boys and 22 girls aged 4-5 years. These expected numbers are split equally across CCGs.³⁷

Prevalence amongst school children

The school census is a statutory return taking place during autumn, spring and summer terms which includes all maintained schools, academies and non-maintained special schools. In 2015 12.6% pupils received SEN support in England, comparing to 11.2% (8,000 pupils) in East Sussex.³⁸

Among school age children, the national prevalence rate of learning disabilities in schools in 2014 was 33.7 per 1,000 pupils, significantly higher than the East Sussex rate of 20 per 1,000 pupils. This does not include pupils with specific learning difficulties such as dyslexia.³⁹ In 2015, 1,535 pupils in East Sussex have a learning disability (excluding those with a learning difficulty), and 790 have ASD (Table 5 on next page)

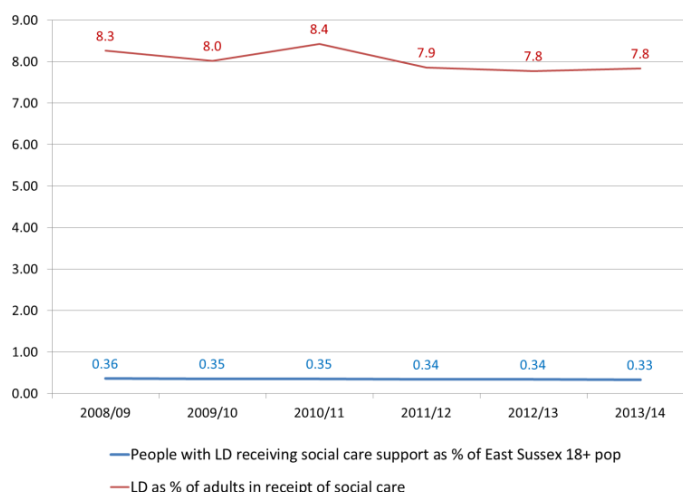
Number of adults known to council LD teams

There were 1,440 people with learning disabilities aged 18 or over receiving long term support from adult social care between December 2014 and November 2015. This equates to 0.3% of the population of East Sussex.⁴⁰

Estimates suggest that between 20% and 30% of people with learning disabilities known to local authorities are estimated to also have an autistic spectrum disorder (ASD).⁴¹ This would equate to between 290 and 435 people known to services with a learning disability and ASD.

Between 2008/09 and 2013/14, of all adults receiving social care, the proportion who have a learning disability fell from 8.3% to 7.8% (figure 5). This reflects a fall in the proportion of adults with learning disabilities receiving social care support as a percentage of the overall adult population of East Sussex. However, the numbers receiving social care support have only fallen slightly over this time frame from 1,485 in 2008/09 to 1,425 in 2013/14⁴², yet they constitute a smaller proportion all those living in East Sussex due to population increases over time. For example between 2008/09 and 2013/14 the population of East Sussex grew from 511,092 to 539,766.

Figure 5: Percentage of adults with learning disabilities receiving social care support 2008/09 to 2013/14



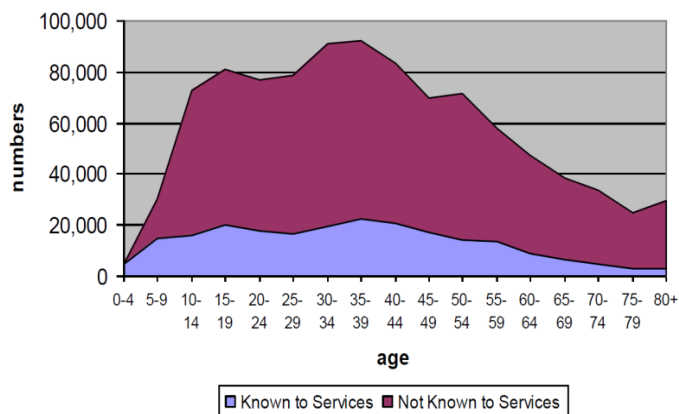
Source: NASCIS RAP P1/ONS mid-year estimates

It is important to bear in mind that people with learning disabilities who are not known to specialist services may still have some significant support needs, as evidenced in recent NICE guidance.⁴³ For example, in a follow-up of the National Child Development Study cohort to age 33, people with mild learning disabilities were significantly more likely than their

peers to be still living with their parents, be unemployed, have literacy and numeracy problems and to experience high levels of psychological distress.⁴⁴

Figure 6 shows the estimated number of people with a learning disability not known to services, including those with mild disabilities and those who may not require services.

Figure 6: Estimated number of people with learning disabilities in England



Source: Emerson and Hatton, 2004

Children and Young People

SEN provision

The Special Educational Needs and Disability (SEND) provisions in the Children and Families Act 2014 were introduced on 1 September 2014. From this time, any children or young people who are newly referred to a local authority for assessment are considered under the new Education Health Care (EHC) plan assessment process.

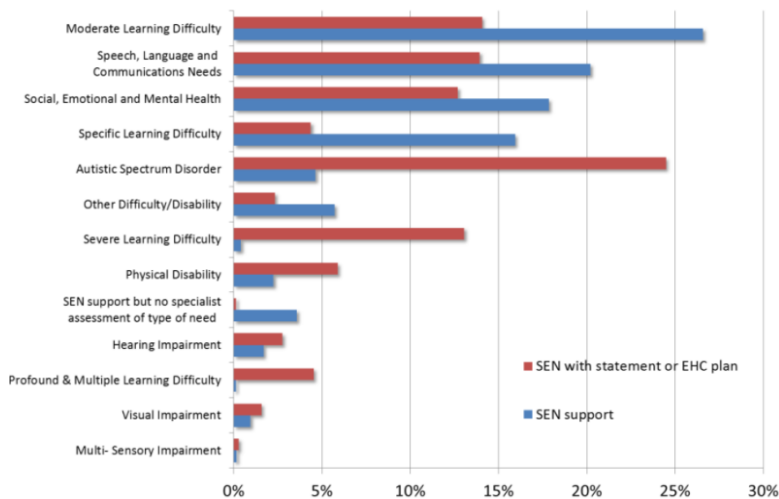
A pupil has a statement of SEN or an EHC plan when a formal assessment has been made. A document is in place that sets out the child's needs and the extra help they should receive. In addition, the previous 'School Action' and 'School Action Plus' categories were replaced by a new category 'SEN support'.

The proportion of pupils with a statement/EHC plan in England has remained at 2.8% since 2007.⁴⁵ The 2015 school census for East Sussex recorded that there were 2,340 pupils with statements or EHC plans (based on where the pupil attends school), equating to 3.6%.

Nationally in 2015, moderate learning disability was the most common primary need for those with SEN support (Figure 7), with ASD most common for those with SEN who have a statement/EHC plan. Due to the

changes in coverage and classification, it is not possible to directly compare with previous data.

Figure 7: Proportion of pupils with statements/ EHC plans and SEN support in England by primary type of need, January 2015



Source: DfE, 2015

For pupils who are residents in East Sussex and attend mainstream schools, academies and free schools, special schools and special academies in East Sussex this equates to (Table 6):

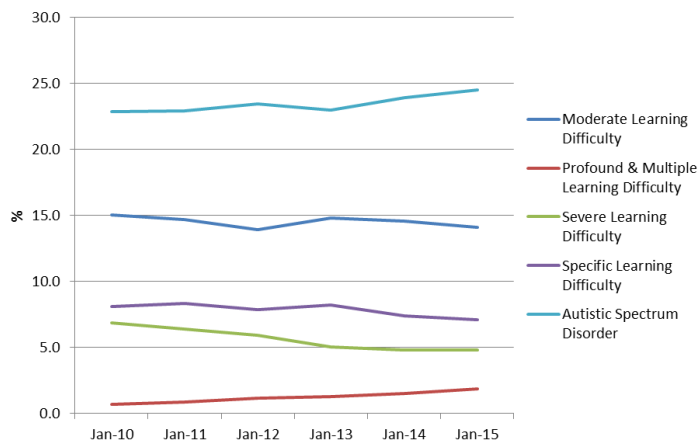
Table 6: Pupils with SEND recorded in the Jan 2015 School Census by Primary Need and SEN Provision

Primary SEN type	SEN support	EHC plan/statement	Grand total
Moderate Learning Difficulty	965	235	1,200
Profound and Multiple Learning Difficulty	10	90	100
Severe Learning Difficulty	15	220	235
Autistic Spectrum Disorder	260	535	790
ALL SEN TYPES	7,040	2,340	9,370

Source: ESCC School Census, 2015

As a percentage of all pupils with statements or EHC plans maintained by East Sussex⁴⁶, pupils with ASD and profound and multiple learning disabilities have increased over the last five years (by 1.6% and 1.2% of the total respectively), while pupils with severe learning disabilities have fallen by 2.1% of the total (Figure 8).

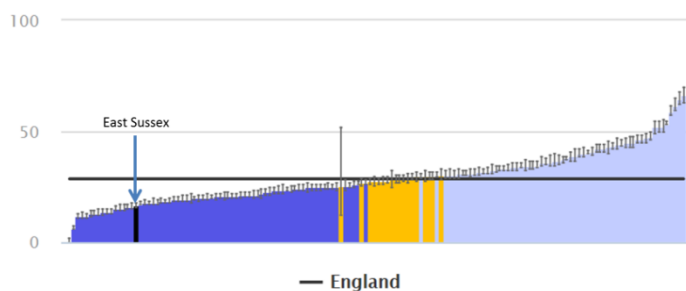
Figure 8: Percentage of all pupils with statements/EHC plans or SEN support who have a learning disability or autism, January 2015



Source: ESCC School Census, 2015

In 2014/2015, East Sussex had a significantly lower rate of children with moderate learning disabilities known to schools than nationally (16.7 per 1,000 compared to 28.6 per 1,000), as well as a lower rate of children with severe learning disabilities known to schools (3.3 per 1,000) than nationally (3.8 per 1,000). At a rate of 16.7 per 1,000 for moderate learning disability, East Sussex has the third lowest rate in the South East and the 20th lowest rate out of the 148 authorities in England (Figure 9). The rate of children with autism known to schools (11.3 per 1,000) is similar to the national rate (10.8 per 1,000).⁴⁷

Figure 9: Proportion of children with moderate learning disabilities known to schools per 1,000, 2014



Source: DfE, 2015

Of all pupils in East Sussex with statements, EHC plans or receiving SEN support in 2015, 35% of those in primary school, 60% in secondary school, and 60% in special schools are being supported for a primary reason of learning disability, learning difficulty or autistic spectrum disorder (ASD). (Table 7).⁴⁸

Table 7: Pupils with SEND by type of school, 2015

	Mainstream primary	Mainstream Secondary	Special School
Specific Learning Difficulty	12.4%	33.5%	1.4%
Moderate Learning Difficulty	15.2%	15.1%	11.3%
Severe Learning Difficulty	0.6%	0.5%	18.2%
Profound & Multiple Learning Difficulty	0.2%	*	8.4%
Autistic Spectrum Disorder	6.7%	10.9%	20.3%
Social, Emotional and mental health	17.9%	18.6%	16.3%
Speech, language and communication needs	30.4%	12.6%	14.1%
Physical disability	1.9%	2.5%	7.1%
Other	14.6%	6.2%	2.9%
Total Pupils with SEN support	4,332	2,715	1,086

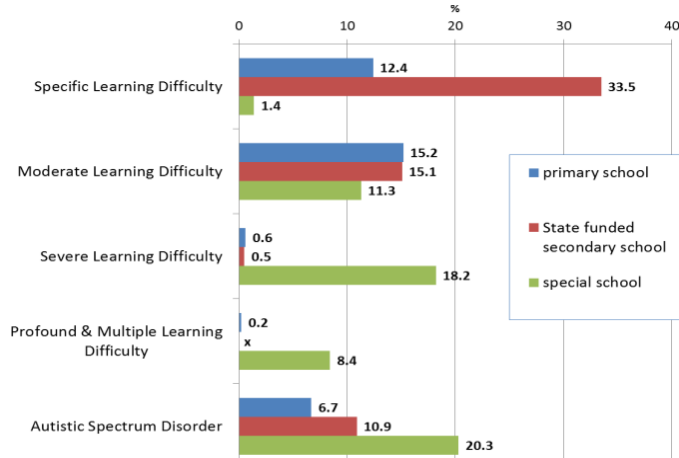
Source: DfE, 2015

As a percentage of the primary school population with SEND, East Sussex has similar proportions of pupils with profound (0.2%) and severe (0.6%) learning disabilities compared to regionally (0.2% and 0.6% respectively), and lower proportions of pupils with moderate learning disabilities (15% compared with 23% regionally and 25% nationally).

This lower proportion of pupils with moderate disabilities is replicated in secondary schools (15% in East Sussex compared to 22% regionally and 25% nationally) and in special schools (11% in East Sussex compared to 18% regionally and 16% nationally).⁴⁹

Within primary schools the greatest proportion of children with a learning disability or ASD are being supported for a moderate learning disability (15%), in secondary schools the greatest proportion of support is for specific learning difficulty (33.5%) and in special schools it's for ASD (20%) and severe learning difficulty (18%) (Figure 10).⁵⁰

Figure 10: Percentage of all pupils with statements/EHC plans or SEN support with a learning disability or autism, January 2015, by school type



Source: DfE, 2015

x - <5 pupils

In East Sussex there are 190 schools in total: 155 LA maintained schools; 33 academies; one mainstream free school and one studio school. 2.6% of pupils in primary school (including both LA maintained and academies) have a learning disability or ASD (excluding specific learning difficulties). This compares to 2.8% of pupils in secondary schools and 68% of pupils in special schools.

As a percentage of all students, a greater proportion of those in academies have a learning disability or ASD (5%) than in LA maintained schools (3%). The percentage of pupils with ASD in primary academies (3.5%) is slightly higher than LA maintained schools (2.5%) and over twice the proportion of pupils in secondary academy schools (3.7%) have a learning disability or autism than in LA maintained secondary schools (1.7%). 87% of pupils in special academies have a learning disability or ASD compared to 57% in LA maintained special schools.

Funding for SEN needs

Within schools in East Sussex pupils may be allocated additional funding if they have additional needs outlined in a statement or an EHC plan which requires high needs 'top-up funding'. This 'top-up funding' applies to East Sussex mainstream schools, special facilities and special schools (including mainstream academies, free schools and special academies). This is relevant for all pupils on the roll at one of the above schools.

Top up funding is separated into 10 bands, Band 1 being the lowest level of top up funding and Band 10 being the highest level. This is a proxy for the level of needs of children in schools across the county. Within mainstream primary and secondary schools Band 1

attracts no additional funding for a pupil with a Statement/EHC Plan as the needs of the pupil have been assessed and can be met from within elements 1 (basic per pupil funding) and element 2 (additional support funding) of the schools own delegated budgets.⁵¹

High needs funding also applies to other settings, such as Early Years settings. For example, nurseries and childminders can apply for an extra 15 hours of support per week to help meet additional needs through the Early Years Inclusion Support Fund. The information below describes top up funding for East Sussex mainstream schools and special schools, including academies, free schools, special academies and special facilities. The snapshot described below only includes East Sussex resident pupils in these settings.

Since April 2015 special schools have moved to a single top-up value per pupil, and there is currently consultation ongoing into the banding structure of mainstream schools. In January 2015, 681 pupils in mainstream primary schools were assessed as requiring top up funding, and 584 pupils in mainstream secondary schools (this includes pupils aged over 16 where there is further education provision attached to a secondary school).

The data outlined below describes a snapshot of top up funding captured in January 2015 (East Sussex resident pupils in these settings; all SEN primary need types).⁵² This indicates that the greatest numbers of pupils funded in primary and secondary mainstream schools were Band 2 (50%) (Table 8). However, this differs according to school type, with the greatest proportion of pupils with a statement or ECHP in primary schools funded at Band 2 (59.3%), compared to 54.8% of pupils funded at Band 1 (no additional funding) in secondary schools.

Table 8: Percentage of all pupils allocated top up funding by band and type of school, January 2015

Band	Mainstream primary	Mainstream Secondary	Total mainstream
1	28.2%	54.8%	40.5%
2	59.3%	39.9%	50.3%
3	10.6%	3.9%	7.5%
4	1.7%	0.2%	1%
5+	0.3%	1%	0.6%
Total Pupils	681	584	1265

Source: Local Authority Core Pupil Database (sen module)

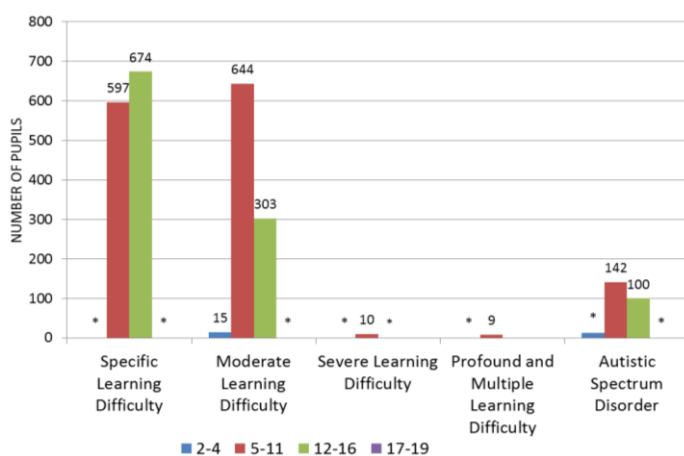
Across all East Sussex mainstream schools in January 2015, 9 pupils were funded for more complex needs

(Band 5 or above)⁵³. In total, 1,038 East Sussex resident pupils received top-up funding across all Bands in special facilities and special schools as at January 2015.

Age

Of the 2,525 pupils with a learning disability or ASD receiving SEN support in 2015, over half (55%) were aged between 5 and 11 years, while 2 in five (42%) were aged 12-16 years. Pupils ages 5-11 were twice as likely as those aged 12-16 to be receiving SEN support for a moderate learning disability and nearly 1.5 times as likely to have ASD (figure 11).

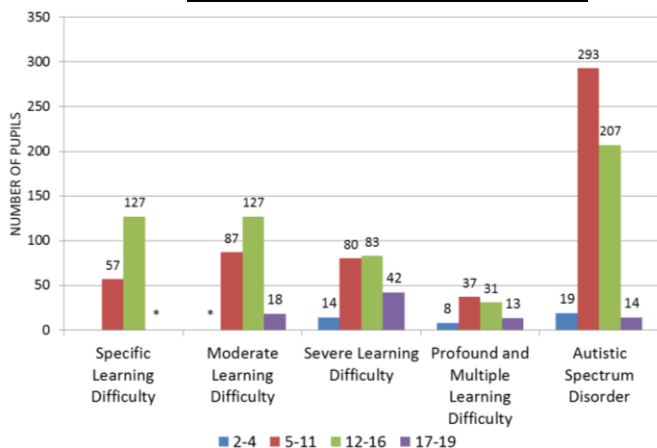
Figure 11: Pupils receiving SEN support by primary need and age, January 2015



Source: ESCC School Census, 2015

Of the 1,260 pupils with a learning disability or ASD with an EHC plan or statement in 2015, pupils aged 12-16 were most likely to receive support for ASD. 12-16 year olds were more likely than any other group to be supported for a specific learning difficulty or a moderate learning disability (figure 12).

Figure 12: Pupils with an EHC plan or statement by primary need and age, January 2015



Source: ESCC School Census, 2015

School leavers

In January 2015 there were 96, 17-19 year olds with support for a learning disability or ASD, 87 of who had an EHC plan or statement. Of those with a statement or EHC plan, 17-19 year olds are twice as likely to be receiving support for a severe learning disability as any other learning disability or difficulty (Figure 12).

Gender

Boys (2,530) are twice as likely as girls (1,260) to have SEN support, an EHC plan or a statement, and nearly five times as likely to be receiving support for ASD. Boys are more likely than girls to have all types of learning disability and are twice as likely to have a severe learning disability or a specific learning difficulty. 90% of girls receiving SEN support are supported for specific learning disability and moderate learning disability compared to 86% of boys. Boys are most likely to have an EHC plan or statement for ASD (48%), and girls for moderate learning disability (26%) followed by ASD (25%).⁵⁴

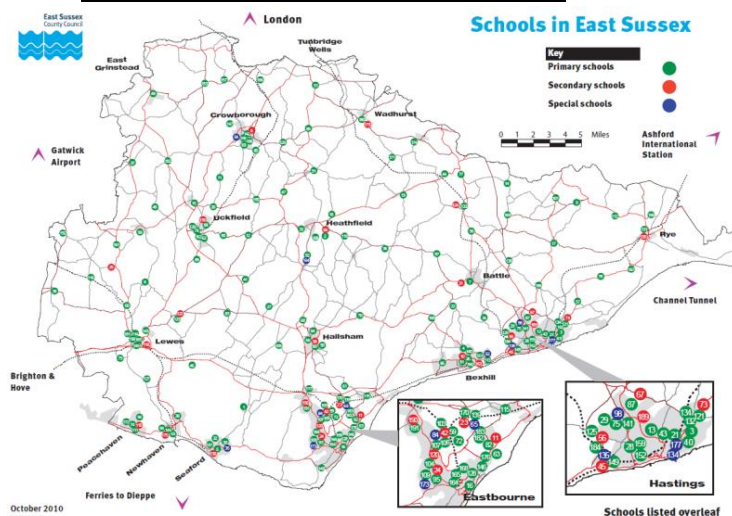
Ethnicity

93% of pupils who have a learning disability or ASD are of White ethnicity (reflecting the general profile of the East Sussex population), and the most prevalent Black or Minority Ethnic (BME) group within this cohort are pupils of mixed ethnicity (4%). Pupils of all ethnicities are most likely to have SEN support for a specific learning disability and an EHC plan or statement for ASD.⁵⁵

Location

Figure 13 shows the location of primary, secondary and special schools in East Sussex, illustrating that the greatest concentrations of special schools are located in the Hastings and Eastbourne areas.

Figure 13: Location of schools in East Sussex

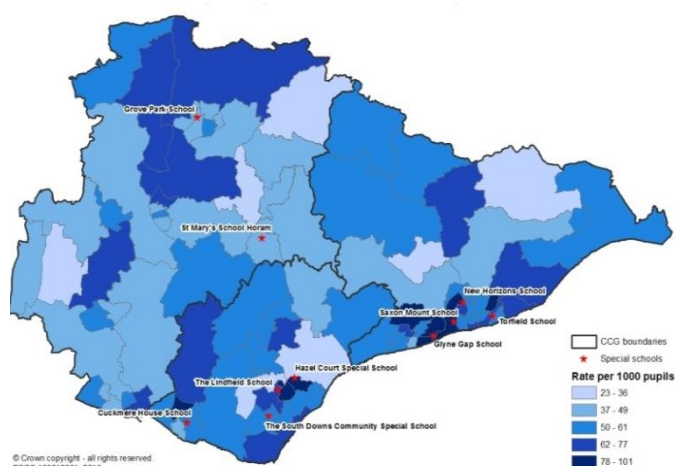


Source: ESCC public health intelligence team, 2015

Figure 14 indicates that over half the wards with the highest rates of pupils with a learning disability or ASD have a special school located within them. This could potentially be due in part to the locating of schools where there is most need, or to people moving closer to areas where there is more known support.

If compared to Figure 15 which shows the IDACI score (Income Deprivation Affecting Children Index) of each ward, there is little obvious correlation across East Sussex as a whole between deprivation and wards the highest rates of pupils with a learning disability and/or autism. However, rates of pupils with learning disabilities are higher in areas of highest deprivation around Hastings and Eastbourne.

Figure 14: Rate of East Sussex pupils with a learning disability and/or autism by pupil ward of residence, Jan 2015



Source: ESCC public health intelligence team, 2015

East Sussex currently has a total of 19 children and young people in residential schools in the Sussex area; and a further 25 children and young people in residential schools out of area.⁵⁶

Deprivation

Research demonstrates a strong relationship between disability, low income and social exclusion among families who have a disabled child.⁵⁷

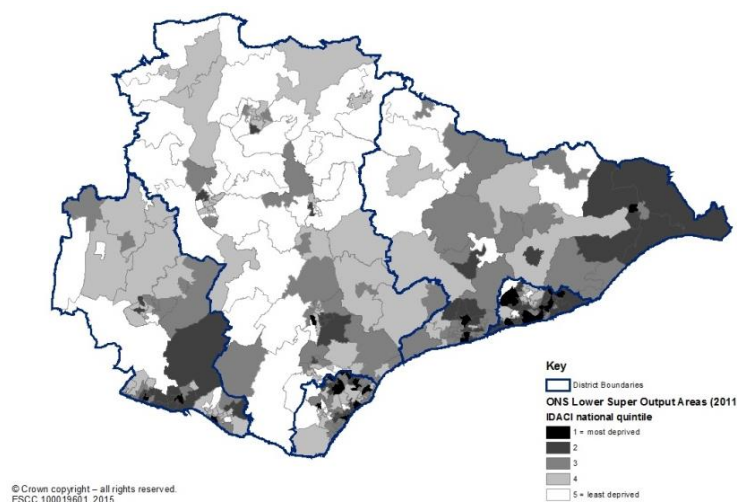
Nationally, among children and young people, there is a fourfold difference in prevalence of moderate learning difficulties between deprived homes in deprived areas and non-deprived homes in non-deprived areas. For severe learning disabilities it is twofold and for profound and multiple learning disabilities it is slightly less than this.⁵⁸

Figure 15 maps the Income Deprivation Affecting Children Index (IDACI) across East Sussex. IDACI covers only children aged 0-15 living in income deprived

households, scored as a proportion of all children aged 0-15 living in income deprived families.

16,000 or 17% children are affected by income deprivation in the county; this is higher than the regional average of 14% but lower than the average for England as a whole (20%). However, there is much variation within the county. Almost 3 in 10 children in Hastings are living in families affected by income deprivation compared to less than 1 in 10 in Wealden.⁵⁹

Figure 15: East Sussex Income Deprivation Affecting Children Index (IDACI), IMD 2015



Source: ESCC public health intelligence team, 2015

Of the 64,620 pupils in East Sussex in 2015, 8,400 were eligible for free school meals. Approximately a quarter (24.5%) of children with a learning disability or ASD are eligible for free school meals (FSM), compared to 26% of all pupils with SEN, and 11% of pupils who are non-SEN.

Of those with learning disabilities or ASD with a statement or EHC plan, pupils with moderate learning disabilities are most likely to be eligible for free school meals (36%) followed by pupils with severe learning disabilities (30%).⁶⁰

Across all ages, levels of SEN provision, and subjects, pupils eligible for free school meals (FSM) are less likely to achieve expected levels of development than those not eligible.⁶¹

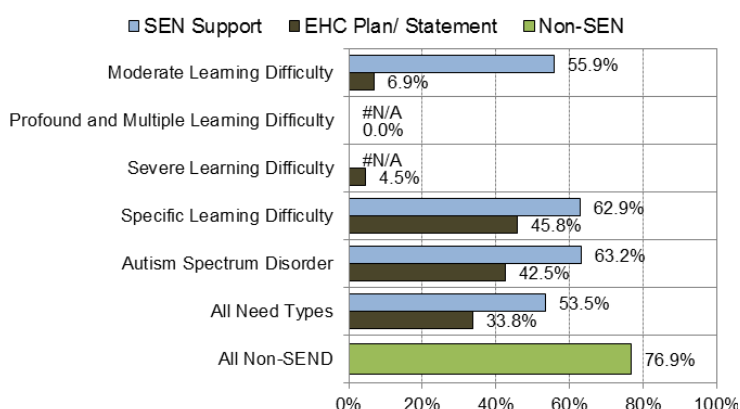
Educational Attainment

Nationally, those with a special educational need associated with learning disabilities have much poorer attainment than those without: over a third have no formal qualifications, compared to 1 in 10 overall. Between 2007 to 2011 the percentage of pupils achieving expected level of attainment in English and

maths has improved nationally, although this is just 15% of those with a moderate, 3% of those with a severe, and 2% of those with profound and multiple learning difficulty, compared to 74% for all pupils.⁶²

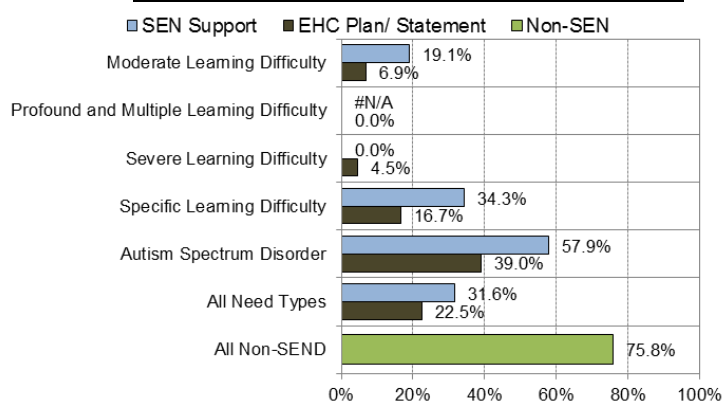
According to the 2015 school census, in East Sussex 77% of non-SEND pupils achieved expected progress in English between key stage 2 and 4 (ages 7 to 16) and 76% achieved expected progress in maths (Figures 16 and 17).

Figure 16: Percentage of pupils who have made expected progress in English between KS2 and KS4



This compares to 4.5% pupils with a severe learning disability and 0% pupils with a profound and multiple learning disability achieving expected progress in English and maths, and compares to 33.8% of all pupils with an EHCP or statement achieving expected progress for English, and 22.5% for achieving expected progress for maths.⁶³

Figure 17: Percentage of pupils who have made expected progress in maths between KS2 and KS4



Continuing health care

A continuing care package is required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone. It does not include children and young people with care needs

that may be met appropriately through existing universal or specialist health services. As of April 2016, 50 children are funded for continuing health care, but there is no information available on whether children have a learning disability⁶⁴.

Looked after children

Looked after children, as defined by the Children Act 1989, are either looked after or in the care of a local authority, or are provided with accommodation for more than 24 hours by a local authority. While this cohort can have a wide range of impairments, a “typical” child in residential care tends to be a teenage boy with persistent development disorders such as autism, and at least one other disability.⁶⁵

Nationally, over 1 in 5 looked after children have a special educational need associated with learning disabilities⁶⁶. The risk of a child being looked after continuously for a year or more has been calculated from the national pupil database to be 2% for moderate learning disability, 2.5% for severe learning disability and 3.1% for profound learning disability⁶⁷.

As of July 2015 there were 540 looked after children in East Sussex, 430 of who have been in care for at least a year and 103 have a known disability.⁶⁸ Applying national estimates to our local population of children looked after for a year or more, we would expect:

- 9 looked after children with a moderate learning disability (MLD)
- 11 looked after children with a severe learning disability (SLD)
- 13 looked after children with a profound multiple learning disability (PMLD)

Transition

Children are surviving longer with conditions they would previously have died from in childhood and so support with the transition from children to adult services is becoming a more prevalent issue.⁶⁹

Transition services support young people and their families through the transition into adulthood to ensure that all young people have the same rights and opportunities.⁷⁰ Health-related quality of life for young people with complex health needs and disabilities can be improved by a good transition⁷¹, and a well-planned transition improves health, education and social outcomes for young people.⁷²

This time of transition is described as a “cliff edge” for young people and their families who feel unprepared for the process and have anxiety about whether the services will fall away when the child becomes 18. The transition from child to adult services is further complicated by the differing ages at which young people move from one service to the other, and this

alongside transitions in their education means young people may be going through several transition processes at once.⁷³

National evidence shows that young people with a diagnosis of autism but with no learning difficulties (that is, those with 'high functioning autism' (HFA) or Asperger's syndrome (AS)) whilst not eligible for support from adult social care, do have significant support needs to enable them to successfully transition into adulthood and parents can often find themselves, often reluctantly assuming a keyworker role.⁷⁴ National evidence suggests that with the right planning and support through transition, and with knowledge to make informed choices, for example of supported living options,⁷⁵ more adults with autism would live independently.⁷⁶

The social Care Transition Service is for young people aged 16-25 who have SEN and are eligible for adult social care. Those eligible for support from the Transition Team include those:

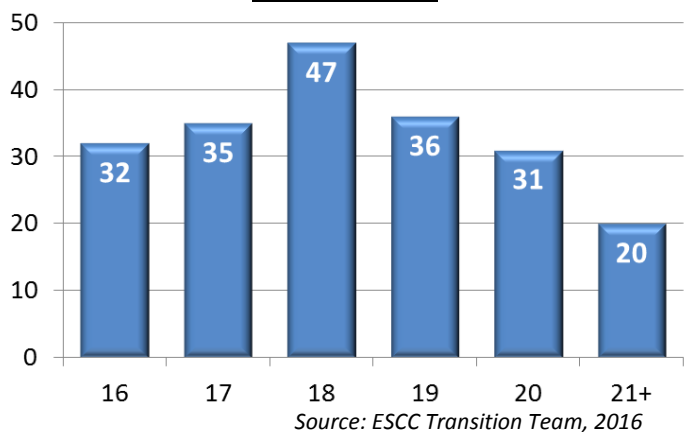
- In need of community care services at 18+ years and
- Have severe and enduring disability and
- Have an LDA (Learning difficulty assessment) or EHCP.⁷⁷

Young people move into the transition service at age 16 but the transition team will be aware of young people from the age of 14 years to aid planning.

The East Sussex Transition Service became operational in 2011 to support young people who have SEN and are eligible for adult social care. Social Workers support complex cases and Looked After Children while less complex cases are supported by resource officers. These individuals remain the allocated worker for the young person until the age of 19 or until 25 years if appropriate. Once adult social care funding has been agreed and the care package is ready to be implemented the individual is transferred to the appropriate adult social care team (usually in their early 20s). Anyone referred to the transition service at age 18 is redirected to Adult Social Care.¹²⁴

There is no data readily available specifically on young people with learning disabilities supported by the Transition Team, although it is anticipated that approximately 85% of the caseload are young people whose primary need is as a result of a learning disability.⁷⁸ As at 9th February 2016 there were approximately 200 young people supported by the Transition Service, with the most prevalent age group being those aged 18 years (figure 18). Of the total caseload approximately 6.5% are looked after children.

Figure 18: Caseload of the Transition Service as at 9th Feb 2016, by age



The Transition team receives an average of 34 new referrals a year from Children Disability Services (CDS), and have received an additional 70 external referrals (from parents, other children's teams, schools, colleges, GPs etc) since February 2014, all of which concern children not previously known to CDS.⁷⁹

Adults (18+)

Adult Social Care

Adult Social Care Assessment Criteria

In East Sussex, assessment for adult social care services is based on both the "Valuing People" definition of learning disability, as well as assessment for social functioning and communication skills to determine an individual's needs. An initial assessment for adult social care services will be undertaken depending on whether an individual is considered to have a learning disability based on the following criteria⁸⁰:

1. The person being referred attended a school for children with severe learning disabilities (e.g. Glyne Gap, Hazel Court or Grove Park School in East Sussex)
2. The person is known to child disability services
3. The person has previously been open to a learning disability assessment team
4. The individual is diagnosed as having a learning disability – who provided the diagnosis?
5. There has been a formal assessment of IQ – was the measure below 69 and have affecting factors been taken into account?
6. The person was referred as a direct result of the learning disability having been referenced in the above indicators.

A referral may not be appropriate if:

- there is indication that the person has the ability

- to understand new complex information,
- under usual circumstances the person manages with no other existing levels of support,
- the referral is due to other influences such as mental health or older age,
- the individual's needs are adequately accounted for by a significant speech, hearing or vision impairment or physical or mental health problems,
- the person has a specific learning difficulty such as dyslexia,
- there is cognitive deterioration associated with schizophrenia or alcohol or substance misuse (in the absence of a learning disability),
- there has been acute head injury during childhood or adulthood,
- a person with Autistic Spectrum Disorder has average or above average intelligence,
- the individual has educational qualifications such as A-levels or a university degree.

Where the primary need is unclear, the service that can best meet a person's needs takes the lead role within joint working arrangements.

Community Learning Disability Teams

The Integrated Community Learning Disability Teams (CLDT's) in East Sussex assess the support needs of adults with learning disabilities and their carers' and plan and coordinate support. CLDT's work with individuals, their families and representatives, service providers with a clear focus on assessment, personalised support planning and review. The teams work preventatively with individuals who may be at risk of admission to in-patient assessment and treatment settings and facilitate on-going review and discharge planning for customers residing in in-patient facilities to ensure high quality care and timely discharge⁸¹.

CLDT's have a lead role in: the assessment and management of risk and mental capacity; ensuring risk is assessed in a positive manner; ensuring that support plans are effective, cost effective and regularly reviewed; that key outcomes for customers are being delivered and that vulnerable people are safeguarded from abuse.

CLDT Strengthened Crisis Response services provide service users in crisis, including those with dual and/or complex needs, for example, East Sussex has two CLDTs (East and West) where ASC and SPFT staff are co-located with joint referral meetings and case discussions (not integrated) with one integrated assessment process, a shared single care plan and review process⁸².

Safeguarding

Safeguarding means protecting people's health, wellbeing and human rights, and enabling them to live free from harm, abuse and neglect.⁸³ In East Sussex the Safeguarding Adults Board (SAB) is accountable to the ESCC Scrutiny Committee and through the Lead Member for Adult Social Care. In 2014/15 33.5 per 1,000 adults with a learning disability on GP registers were referred for safeguarding. This is significantly lower than nationally (62.2) and regionally (66.3).⁸⁴

Direct Payments

People can choose for the local authority to commission care and support on their behalf or can choose to take a 'direct payment'⁸⁵ where the council pays money into their bank account for them to use to buy the support they need. In 2014/15, 11.6% of adults with long term social services support who receive direct payments or part-direct payments had a learning disability. This is significantly lower than England (17.4%) and the South East (15.6%).

Long Term Support

In 2014/2015 the rate of adults (18-64) with a learning disability who received long term support from East Sussex County Council was 3.44 per 1,000 population.⁸⁶ Long-term support encompasses any service or support provided with the intention of maintaining quality of life for an individual on an ongoing basis. This support is allocated on the basis of an assessment of eligibility criteria and is subject to regular review.

The following information primarily comes from the Liquid Logic Adult's System (LAS) database that holds information about Adult Social Care clients and carers.

Between December 2014 and November 2015 1,271 working age adults and 170 older people with a Primary Support Reason (PSR) of Learning Disability Support, and 170 older people with a PSR of Learning Disability Support received Long Term Support from Adult Social Care.⁸⁷ Of this number:

- 61% were in receipt of community based services such as day care and home care (provided by the Community Support Team and external providers)
- 37% were in residential care, and
- 2% were in nursing care.^{88,89}

Adult Social Care Funded Services

Adult Social Care Directly Provided Services include day and residential care, respite and domiciliary care for those living at home, and ESCC in-house services. Between October 2015 and September 2016, 1,751

adults received an ASC funded services. This includes both those who have a Primary Support Reason (PSR) of learning disability, and those clients with no PSR recorded but where a service was funded from a learning disabilities budget. This number breaks down into the following (Table 9):

Table 9: Number of people receiving an adult social care funded service 1st Oct 2015 to 30th Sept 2016 by service type

Directly Provided Service	Number of clients	% of total number
Day care	537	19%
Residential/Nursing (not respite)	595	21%
Respite	198	7%
Supported Living/Community Based Services	379	13%
Shared Lives	120	4%
Homecare	58	2%
Other services	966	34%

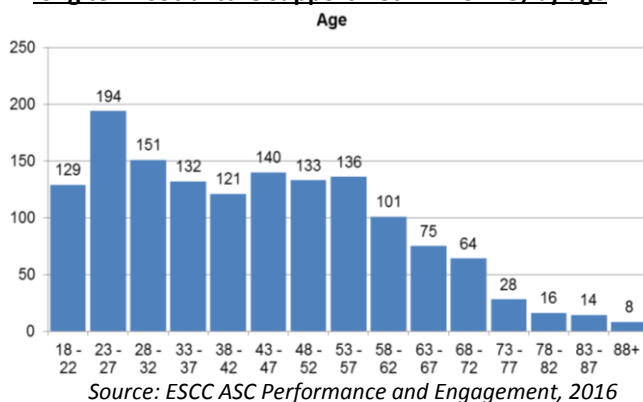
NB: People may receive more than one service type

One third of those receiving ASC funded services were in receipt of 'other services' which includes carers community based services, direct payments, equipment, extra care, meals, telecare, travel, and professional support. One in five were in receipt of residential/nursing care.

Age

Of those with a learning disability receiving long term social care support between December 2014 and November 2015, a third (33%) were aged between 18-32 years (Figure 19). Of the total cohort, 88% were of working age and 12% were aged 65 years or older. This broadly reflects the national estimated age profile for adults with learning disabilities.

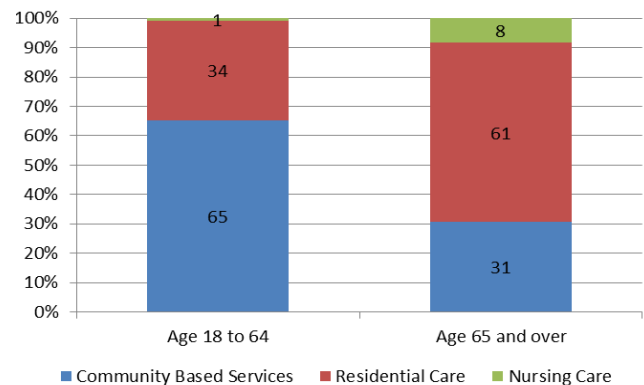
Figure 19: People with learning disabilities receiving long term social care support Dec 14-Nov 15, by age



As a percentage of the total number of people with Learning Disabilities in receipt of social care support in 2013/14, those aged 65 years or older were twice as

likely as those of working age to be in residential care, and 8 times as likely to be in nursing care (Figure 20). Nationally in 2013/14 those aged over 65 years were just under two times more likely to be in residential care and six times as likely to be in nursing care⁹⁰.

Figure 20: % of adults with learning disabilities receiving social care support by placement and age



Gender

Of the 1,441 adults currently receiving learning disability support, 58% are male and 42% female.⁹¹ This corresponds with national evidence that learning disabilities are more prevalent amongst males than females.⁹² Of those receiving learning disability support, 140 have been diagnosed with autistic spectrum disorder. National data suggests that five times as many males as females are diagnosed with autism⁹³, although there is acknowledgement that autistic spectrum disorders are underdiagnosed in females.⁹⁴

Ethnicity

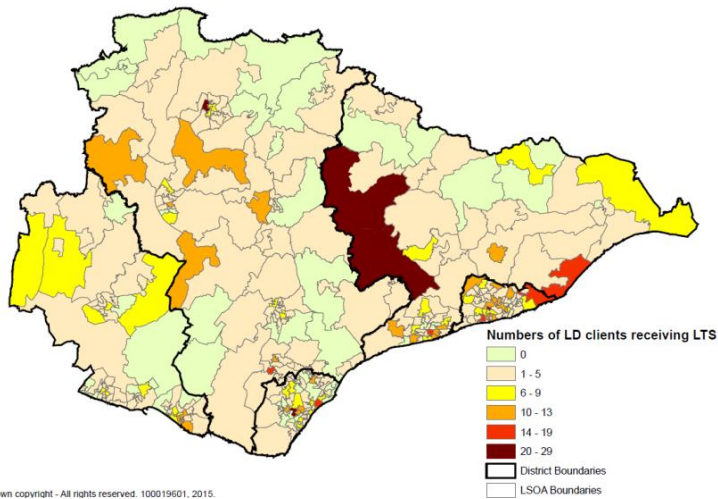
Ethnicity and nationality can influence the prevalence of learning disabilities, with certain ethnic groups and nationalities having higher prevalence rates for certain learning disabilities. For example, children from Irish Traveller and Gypsy/Romany groups are at higher risk for moderate to severe learning disabilities, and Pakistani and Bangladeshi groups are more likely to have profound and multiple learning disabilities than other ethnicities.⁹⁵ 94% of the adults receiving long term learning disability support in East Sussex are White British, with groups identified as being at higher risk of certain types of learning disability representing just 0.2% of this cohort.⁹⁶

Location

Figure 21 shows the number of adults with a learning disability who are receiving long term social care support by Lower Super Output Area (LSOA). An LSOA is an administrative area with an average population of 1,500 people. Care needs to be taken interpreting mapping by LSOA as rural areas with higher densities

of people are more striking on a map, but these areas have the same population as very small, more densely populated urban areas.

Figure 21: Number of learning disability clients receiving long term support by LSOAs (Oct 14-Sep 15)



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Source: ESCC ASC, 2016

The highest concentrations of adults with learning disabilities who are in receipt of long term social care support generally fall into the coastal areas of the county, particularly around Eastbourne, Hastings and West of Hastings in Ore and Marsham Coast. Higher density of social care recipients broadly corresponds with more densely populated areas, although there are higher numbers in some rural areas, such as Darwell and Crowhurst.

Parenting

An increasing number of people with a learning disability are having children^{97,98}, with research suggesting approximately 7% of adults with a learning disability in the UK are parents.⁹⁹ This includes people who have mild disabilities who may not have been identified until after they became parents. It should also be borne in mind that this estimate was made over ten years ago and the study acknowledged that the numbers were rising so it's possible this number is an underestimate. However, using this figure as a very crude estimate would suggest that in East Sussex, approximately 100 adults with learning disabilities are parents.

The government White paper *Valuing People: A new three year strategy for people with learning disabilities*¹⁰⁰ states that:

"People with learning disabilities can be good enough parents and provide their children with a good start in life, but may require considerable help to do so."

Research suggests an increase in the number of

families where a parent has a learning disability coming to the attention of service providers in health, education and welfare¹⁰¹. However, most parents with a learning disability have mild to borderline cognitive impairments¹⁰², and individuals with a mild learning disability are often difficult to identify, with concern over intellectual ability potentially only raised after they become a parent¹⁰³.

Research shows that parenting skills of people with learning disabilities varies widely¹⁰⁴, and many complex personal, social and environmental factors other than parental IQ underlie parenting challenges which can lead to a child being removed from their parents care^{105,106}.

Many parents with a learning disability are likely to live under conditions that may lead to poorer parenting. Risk factors include low literacy, low income, poor health, access to services or support and social isolation, and can lead to further risks such as depression and parental stress^{107,108,109}.

Children of a parent with a learning disability often display poorer development, associated with adverse pregnancy and birth outcomes such as premature birth and low birthweights¹¹⁰. These outcomes may be related to a range of risk factors, such as: nutritional intake, maternal weight, smoking, use of medications, lack of social support, poorer access to appropriate antenatal care, or mental health problems such as stress, anxiety and depression¹¹¹.

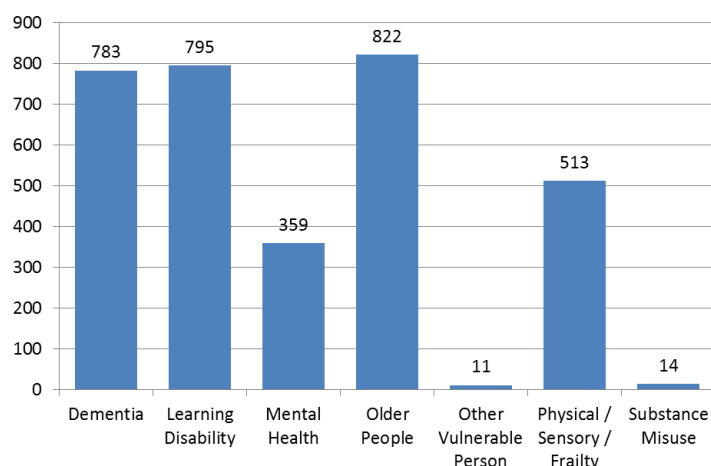
Early intervention,¹¹² and good quality and appropriate antenatal care is therefore vital for women with a learning disability, although services are often not equipped to respond appropriately to specific needs¹¹³.

Adult Social Care Funded Accommodation Placements

The following data is taken from Controcc, the Adult Social Care contract management database, and describes the accommodation placements for adults with learning disabilities which are funded by Adult Social Care. The number of funded placements refers to accommodation placements only and does not include Adult Social Care funded services such as day services, respite and domiciliary care for those living at home, direct payments and ESCC in-house/directly provided services.

As at the 22nd March 2016, Adult Social Care was funding 3,298 placements: 795 (24%) of which are for adults with learning disabilities (figure 23).

Figure 23: Funded adult social care placements by client group, 22nd March 2016



Source: ESCC Control Database, 2016

Of this cohort, 92% (728) are aged 18-64 and 8% over 65 years.

Of the 795 learning disabled adults with funded placements:

- 38% are in supported living or community based services
- 60% are in residential care, and
- 2% have nursing care

As previously outlined, social care is provided according to individual support need so there is no data on severity of learning disability in terms of clinical diagnoses. Not labelling individuals in this way can also help to reduce stigma and discrimination. A useful proxy for assessing need therefore is the level of funding required for a placement.

The following sections outline the profile of those currently in adult social care funded community/supported living placements, in residential care and in nursing care. This does not include Adult Social Care funded services such as day services, respite and domiciliary care for those living at home.

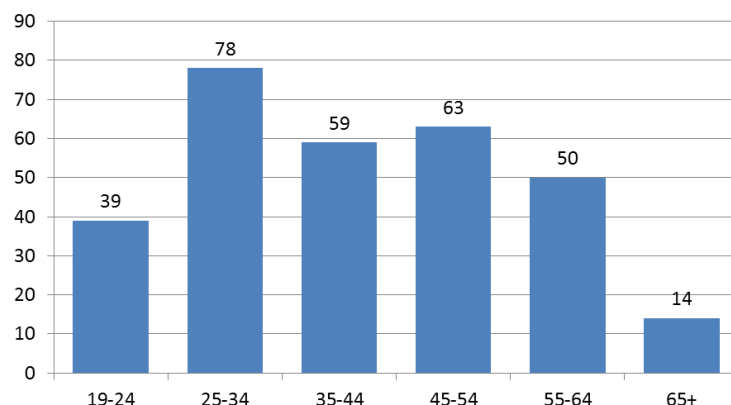
Community/Supported Living Placements

Central to delivering Transforming Care is discharging people from hospital or transferring them to the most appropriate facility, and having an appropriate range of services for people with learning disabilities in the community.¹¹⁴ In 2013-14 £5.3 billion was spent by local authorities on community services for adults with learning disabilities.¹¹⁵

A snapshot of adults in **ASC funded accommodation placements** as at 22nd March 2016 shows that currently 625 adults are funded in Supported Living/Community Based Services by East Sussex, just

under half of this number (303) have a learning disability. Of those with a learning disability in community/supported living placements, almost two fifths (39%) are aged under 35 years, and 13% are aged under 25 years (figure 24).

Figure 24: Age of adults in ASC funded community or supported living placements March 2016



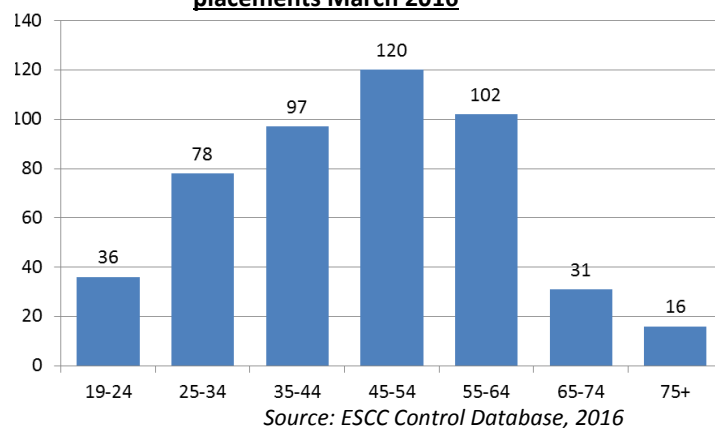
Source: ESCC Control Database, 2016

98% of those with a learning disability funded in community or supported living placements are placed within the County, the remaining 2% are funded out of county.

Residential Care

A snapshot of service use as at 22nd March 2016 shows that currently 1,813 adults are funded in Residential care services by East Sussex, just over a quarter (27%, 480) have a learning disability. In contrast to those funded in community/supported living placements, two thirds (66%) of those with learning disabilities in residential placements are aged between 35 and 64 years, and 7.8% are of the youngest age group (19-24) (Figure 25).

Figure 25: Age of adults in ASC funded residential placements March 2016



Source: ESCC Control Database, 2016

82% (394) of those in residential care placements are placed within the County, and over half (49) of the

remaining 86 individuals are funded out of county. 94% (451) of those in residential placements are in permanent residential care, 16 individuals are in Directly Provided Services, 7 are in short term residential care and 6 are funded for respite care placements.¹¹⁶

Nursing Care

859 adults are currently funded in nursing care placements by East Sussex, 12 of this number have a learning disability, all of whom are supported in permanent nursing care. 8 of those in nursing care placements are placed within the County, and only one has what would be considered higher level needs in terms of weekly placement funding.

Summary of Adult Social Care Funded Accommodation Placements

In comparison to all adults with learning disabilities in funded placements:

- those in community or supported living placements are more likely to be of younger age groups,
- the greatest number of individuals with higher needs as indicated by weekly cost of placement are supported in residential placements
- adults in residential placements are more likely to be placed outside of East Sussex than those in supported living/community placements.
- The average cost of a placement outside East Sussex is highest for those in residential placements.
- Adults in residential care are more likely to be in placements a further distance from East Sussex than those in community or nursing placements.

Wider determinants of health

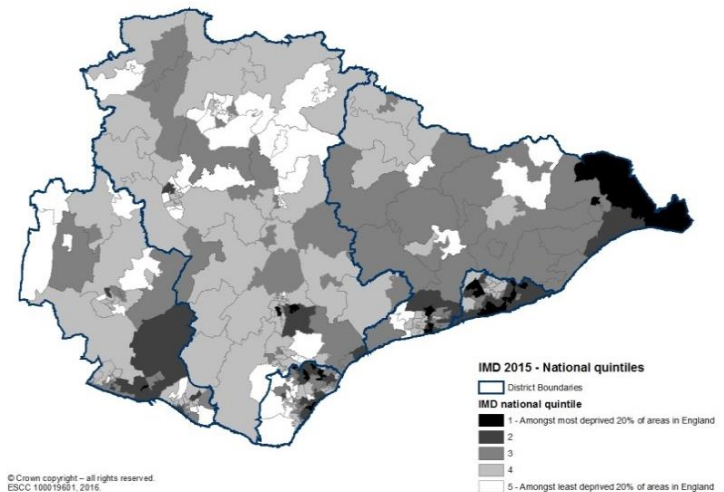
People with learning disabilities, especially people with less severe learning disabilities, are more likely to be exposed to common 'social determinants' of poorer health, such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination.¹¹⁷

Deprivation

In East Sussex, 19 out of 329 LSOAs are among the 10% most deprived neighbourhoods in England: 16 of these are in Hastings, two are in Eastbourne and one in Rother. In Hastings, 30% of LSOAs in the district are among the most deprived 10% nationally, making it one of the 13 most deprived local authorities in

England. However the county also has 22 out of 329 LSOAs in the least deprived 10% in England: 14 of these are in Wealden (Figure 26).¹¹⁸ The mapping of adults with learning disabilities indicates some correlation with areas of deprivation, particularly in rural Wealden and around Hastings and Eastbourne.

Figure 26: Deprivation in East Sussex by LSOA – IMD 2015



Source: DCLG, 2015

Employment

It has been estimated that¹¹⁹, of those known to services in England:

- 28% of people with mild/moderate learning disabilities are in paid employment and,
- 10% of people with severe learning disabilities are in paid employment.
- 15% of autistic adults in the UK are in full-time paid employment.¹²⁰

In East Sussex, nationally submitted data indicates that 7.9% of adults with learning disabilities known to social services in 2014/15 were in paid employment (82 adults).^{121,122} This is significantly better than nationally (5.9%) and similar to the regional average.

Accommodation

Types of accommodation can be divided broadly into 'settled' accommodation, or 'non-settled' accommodation. Settled accommodation refers to secure medium to long term accommodation such as: a tenancy in a local authority property; a tenancy in a housing association property; or a fixed-term assured shorthold tenancy with a private landlord¹²³. Non-settled accommodation refers to a situation where there is low or no security of tenure or residence so individuals may be required to leave at short notice.¹²⁴

Nationally, of all adults with a learning disability who receive social care:

- 73% are living in settled accommodation and
- 27% are in unsettled accommodation
- Just under 6% have an accommodation status unknown to the Local Authority.¹²⁵

In comparison to England East Sussex has significantly lower proportions in settled accommodation, and higher in unsettled accommodation, although the percentage whose accommodation status is unknown to the Local Authority is significantly lower than England. In East Sussex, of the 1,441 adults with a learning disability who receive long term social care support:

- 381 (26%) were living in settled mainstream housing with family/friends
- 484 (34%) were living in another type of settled accommodation such as Supported Living, Adult Placement or Extra Care Housing¹²⁶

Accommodation type has not been recorded for 40 adults with a learning disability receiving adult social care support.

Prison

National figures suggest up to 7% of prisoners have an IQ of under 70. Prisoners with learning disabilities are:

- five times more likely than other prisoners to experience control and restraint,
- three times more likely to experience segregation
- three times more likely to have depression or anxiety.¹²⁷

Data from the education department of HMP Lewes shows that of the current population of 651 prisoners, 110 are currently in education. A fifth of those in education have a self-declared learning difficulty: 15 of whom have dyslexia, and 7 have a self-declared learning disability. A further 5 people stated they had a learning difficulty but declined to say which type.¹²⁸

Health

People with learning disabilities have poorer health than the general population, much of which is avoidable. These health inequalities often start early in life and result, to an extent, from barriers they face in accessing timely, appropriate and effective health care. As well as having a poorer quality of life, people with learning disabilities die at a younger age than their non-disabled peers.¹²⁹

Of the 1,441 adults receiving long term learning disability support between December 2014 and November 2015, 220 had a learning disability medical diagnosis recorded. The most common diagnoses were: Downs Syndrome (90); Epilepsy (28); Autism

(26); Cerebral Palsy (20); Aspergers (15) and Fragile X Syndrome (5).¹³⁰

Continuing health care

A continuing care package is required when an adult has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone. In East Sussex, 13% of the continuing health care caseload (51 adults) have an identified learning disability, requiring support for a number of needs including: tracheostomy, enteral feeding through gastrostomy, skin integrity issues, constipation, epilepsy management and mobility issues. The local policy for continuing health care for adults is that the checklist and decision support tool are not completed until the individual turns 18.

Mortality

The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) found men with learning disabilities die on average 13 years younger than men in the general population and women with learning disabilities die 20 years younger.

The enquiry into the deaths of people with learning disabilities, which was concentrated in the South West of the country, found that 56% of the deaths were considered by experts to be 'premature', based on the specific circumstances of the death, and half were unexpected. Over half of all deaths were from cardio-respiratory causes. CIPOLD data shows that people with learning disabilities are three times as likely as people in the general population to have a death classified as potentially avoidable through the provision of good quality healthcare^{131,132} This suggests that if we improve the quality of healthcare received that we can improve outcomes.

There is no available data to understand the burden of mortality in East Sussex, with numbers likely to be small and therefore not reliable enough for analysis.

Common Conditions

Figures 27 and 28 show the crude prevalence (%) for key health conditions for people of all ages with and without learning disabilities. The greatest health risks for people with learning disabilities compared to those without learning disabilities appear to be for Diabetes, Dementia, need for palliative care, epilepsy, hypothyroidism and severe mental illness (Please note different scales).

Figure 27: Crude prevalence (%) for key health conditions for people of all ages with learning disabilities

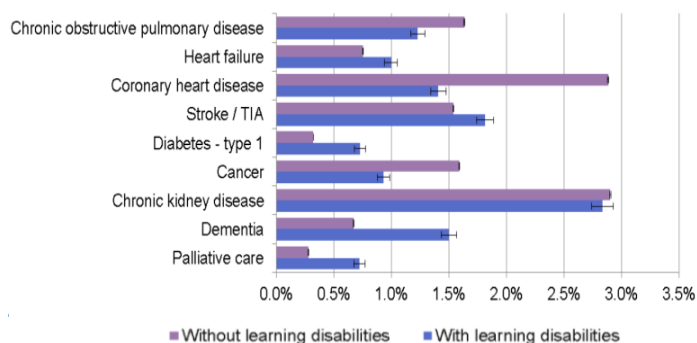
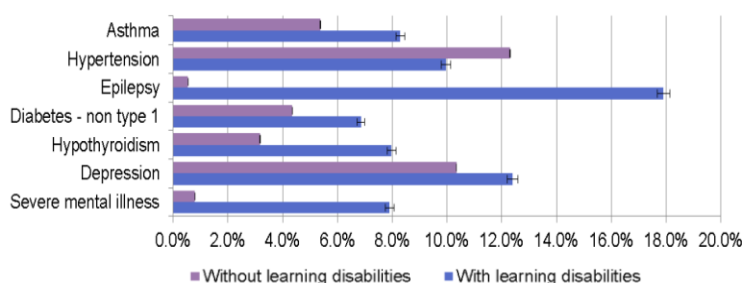


Figure 28: Crude prevalence (%) for key health conditions for people of all ages without learning disabilities



Source: PHE (2016) Glover IHaL conference presentation

The main conditions common to people with learning disabilities have been summarised in Table 9. The local information is taken from a snapshot of adult social care data. Local recording of health condition was introduced in April 2014 and only includes health conditions relevant to a person's social care needs. An individual can have more than one medical condition.

Table 9: Type of diagnosed chronic diseases and conditions^{133,134,135}

What we know nationally
RESPIRATORY DISEASE - Most common cause of death (49% compared to 16% in general population). - Lung problems (from solids or liquids going down the wrong way) account for 14% of all deaths but may be preventable. - Particularly common for those with cerebral palsy
CIRCULATORY DISEASE - As with the general population, coronary heart disease (CHD) is one of the most common causes of death and ill-health (12% of deaths compared to 29% in general population). - Half of those with Down's syndrome have a congenital heart defect

ENDOCRINE DISORDERS

- Diabetes is 1.9 times more common than in the general population, influenced in part by higher rates of obesity.
- Hypothyroidism is common among those with Down's syndrome

EPILEPSY AND CONVULSIONS

- Epilepsy found to be around 20 times more common than in general population.
- Epilepsy & convulsions account for 14% of deaths, many likely to be preventable.
- Seizures are often multiple and also resistant to drug treatment

[In East Sussex 28 of the 220 adults receiving learning disability support who have a medical diagnosis have been diagnosed with epilepsy.](#)

MENTAL ILL HEALTH

- 3x higher prevalence for schizophrenia than general population.
- Anxiety and depression higher than general population, particularly among those with Down's syndrome
- 36% of children with learning disabilities have a psychiatric disorder compared to 8% in general population
- Of all children with a psychiatric disorder, 14% have learning disabilities

[In East Sussex 80 adults receiving learning disability support have a mental health condition.](#)

CHALLENGING BEHAVIOUR

- Aggression and self-injury is common among 10-15% of learning disabilities population, particularly 20-49 year olds
- 1 in 4 people with learning disabilities may self-injure¹³⁶
- Challenging behaviour is likely to result in poorer health and is associated with abuse, neglect and inappropriate treatment

DEMENTIA

- Dementia is more common in the learning disabilities population than the general population (22% compared to 6% for aged 65+).
- Those with Down's syndrome develop dementia 30-40 years earlier than general population

[In East Sussex 12 of the 80 adults receiving learning disability support who have a mental health condition have dementia](#)

PHYSICAL IMPAIRMENTS

- Postural distortion and hip dislocation are more common among the learning disabilities population
- Being non-mobile is associated with 7x increase in

death and being partly mobile with 2x increase
In East Sussex 11.1% (200) adults receiving learning disability support have a long term physical health condition.

VISUAL IMPAIRMENT

- Evidence¹³⁷ suggests that around one in 10 learning disabled adults are likely to be blind or partially sighted, ten times higher than the general population.
- Six out of ten people with learning disabilities need glasses

In East Sussex 2.6% (47) adults receiving learning disability support are visually impaired

EATING AND SWALLOWING

- 8-15% of those with learning disabilities have eating difficulties and may need mealtime support
- 4 out of 10 of those having difficulties have recurrent respiratory tract infections

ORAL HEALTH

- 1 in 3 adults with learning disabilities and over three quarters of those with Down's syndrome have unhealthy teeth and gums
- Those living with families have more untreated decay; those in institutional care have more extracted teeth

CONSTIPATION AND INCONTINENCE

- Constipation common in 17-51% of those in institutional care
- Common side-effect of drugs prescribed, but often missed due to communication problems
- A third of adults and two thirds of children with profound and multiple learning disabilities have difficulties of urinary incontinence
- A quarter of those with profound and multiple learning disabilities have difficulties with bowel incontinence

WOMEN'S HEALTH

- Problems with menstruation in women with learning disabilities may not be appropriately recognised by carers
- There is a greater use of long term contraceptive methods and significantly less use of barrier methods.^{138,139}
- Women with learning disabilities are not given sufficient information and are not fully involved in decisions about contraception^{140,141}
- Earlier menopause, particularly in women with Down's Syndrome,¹⁴² with carers often poorly resourced to help women understand the menopause.¹⁴³

Speech, Language and Communication

Children and young people with speech, language and communication needs have difficulties in understanding and/or making others understand through spoken language, and their speech and language skills may be significantly behind their peers and may be poor or unintelligible. National evidence suggests there is insufficient understanding amongst policy makers, commissioners and sometimes families and carers about the centrality of speech, language and communication as an essential life skill for social, emotional and educational development.¹⁴⁴

Based on School Census Data it has been estimated that around 0.4% of children in the UK aged 5-16 years have speech and language impairments as a primary need.¹⁴⁵ The Royal College of Speech and Language Therapists (RCSLT) estimate that 50-90% of the learning disabled population have communication difficulties and one third of all Speech and Language therapy (SALT) services in the UK are directed at the learning disabled population.¹⁴⁶

Down Syndrome

Down Syndrome is a disorder caused by the presence of an additional chromosome and is the most frequent genetic cause of mild to moderate intellectual and developmental disabilities, occurring in approximately one in every 800 live births. The incidence of Down Syndrome rises with maternal age from one in 1,000 births to mothers aged under 30 years, one in 400 for those aged over 35 to one in 60 by 42 years.¹⁴⁷

Hearing loss, congenital heart disease and vision disorders are more prevalent amongst those with Down Syndrome as well as seizure disorders such as epilepsy. Research indicates a rate of Down Syndrome of 6.25 per 10,000 general population.¹⁴⁸ Between 2011 and 2013 the pooled incidence of Down Syndrome in England was 10.4 per 10,000 live births, and in the South East the incidence was significantly lower at 8.2 per 10,000.¹⁴⁹

Life expectancy of people with Down Syndrome is around 60 years old.¹⁵⁰ Research suggests that as life expectancy is increasing, so are the numbers of people with Down Syndrome developing dementia. According to the Down Syndrome Association, as many as one in three people with Down Syndrome develop dementia in their lifetime, usually as a result of Alzheimer's disease, and usually at a younger age than the general population, at a faster rate, and with a higher presentation of Epilepsy. Figures cited by the Alzheimer's Society suggest as many as 50% of people aged over 60 years who have Down Syndrome will have developed dementia.¹⁵¹

Mental Health

People with learning disabilities have an increased risk of developing psychological problems¹⁵². Children with a learning disability have a:

- 6.5 fold increased risk of mental health problems¹⁵³
- increased risk of developing psychological problems¹⁵⁴
- 2 fold increased risk of experiencing anxiety disorders
- 6 fold increased risk of experiencing conduct disorders.¹⁵⁵
- 1.25 times more likely to try an illicit substance.¹⁵⁶
- six times as likely to experience conduct disorders.¹⁵⁷

Research suggests that at least one in three autistic adults are experiencing severe mental health difficulties due to a lack of support¹⁵⁸

In East Sussex, 4.5% of adults receiving learning disability support have a diagnosed mental health issue: 0.7% dementia and 3.8% another mental health condition. However for 27% a health condition had not been recorded so the prevalence of mental health issues could be higher.¹⁵⁹

Screening

Screening for Down Syndrome

In 2013 there were 1,886 diagnoses of Down Syndrome, 65% of which were made prenatally, a rate of 2.7 per 1,000 births. In the same year there were 728 Down Syndrome live births, a live birth rate of 1.0 per 1,000 live births. For women under 35 years old, the proportion of Down Syndrome diagnoses received prenatally has increased from 55% in 2009 to 62% in 2013, while a fairly consistent 70-75% of diagnoses for women over 35 years were received prenatally. The proportion of women having a termination after a prenatal diagnosis of Down Syndrome has decreased from 92% in 1989-2010 to 90% from 2011 onwards¹⁶⁰.

National research indicates that there are socioeconomic inequalities in the antenatal detection of Down Syndrome, and that subsequent termination rates are much higher than for other anomalies. Termination rates for all anomalies are lower in more deprived areas which impacts on socioeconomic inequalities in live born infants with Down Syndrome, and subsequent neonatal mortality.¹⁶¹

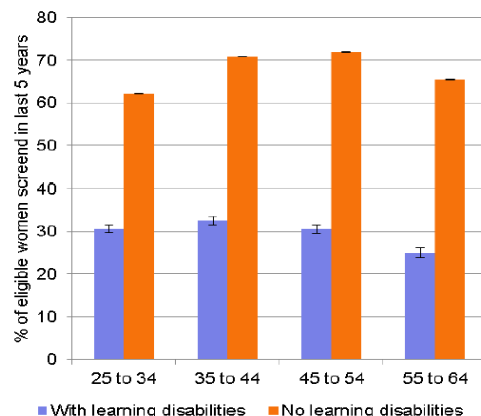
Cervical Screening

Cervical screening uptake in the UK is lower for women with learning disabilities than for those without. Preliminary findings from 2015 Public Health England research on health and care for people with

learning disabilities¹⁶² suggests that 30% of eligible women with learning disabilities have been screened for cervical cancer over the last 5 years, compared to 68% of women with no learning disabilities (Figure 29).

East Sussex is amongst the areas in the UK with the lowest rate of cervical screening uptake for women with a learning disability¹⁶³.

Figure 29: Proportion (%) of eligible women screened for cervical cancer 2000-2015

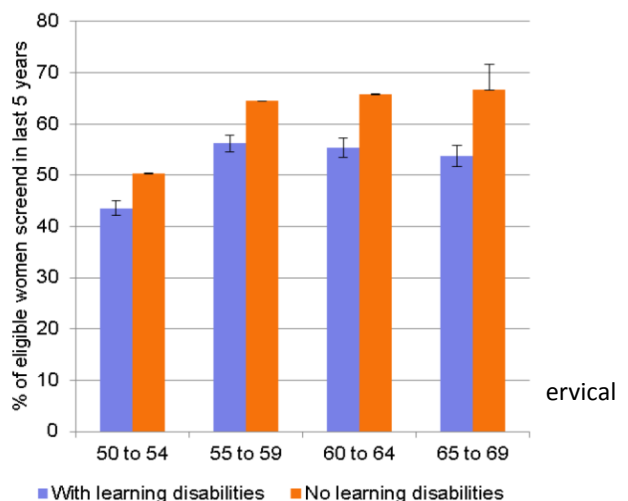


Source: PHE, 2016

Breast Cancer Screening

Breast cancer screening uptake for women with learning disabilities has increased slightly over the last 5 years, but remains on average 10% lower (51%) than for women with no learning disabilities (61%) (figure 30). The difference in uptake for both cervical and cancer screening between women with and without learning disabilities increases with age. Uptake of screening for women with a learning disability in East Sussex is between 41.7% and 48.6%¹⁶⁴.

Figure 30: Proportion (%) of eligible women screened for breast cancer 2000-2015



Source: PHE, 2016

Sexual health

Research has identified that people with learning disabilities often face barriers to experiencing good sexual health.¹⁶⁵ People with learning disabilities may feel overprotected by professionals and family carers which can result in them being unable to express their sexual health needs.

Health Checks

People with learning disabilities have more difficulty than others recognising health problems and getting treatment for them.¹⁶⁶ The free Annual Health Check scheme is for adults and young people aged 14 or above who have been assessed as having moderate, severe or profound learning disabilities, or people with a mild learning disability who have other complex health needs¹⁶⁷. Under the learning disabilities health checks programme GPs are expected to offer regular health checks to people with learning disabilities to make sure important problems are identified and treated.

In 2015/16, there were 2,507 registered patients aged 14 years or over identified as having a QOF diagnostic learning disability in East Sussex. This equates to 0.54% of the 14+ population in East Sussex and compares with 0.46% of the national 14+ population. This percentage varies by CCG, indicating a significantly greater proportion of 14+ year olds with a recognised learning disability in H&R CCG: 0.53% in HWLH CCG, 0.55% in EHS CCG, 0.71% in H&R CCG and 168,169 Table 10 identifies the number of eligible people who received a health check in East Sussex in 2015/16.

As a percentage of people aged 14 years or older on GP learning disability registers in East Sussex, 43% received a health check in East Sussex in 2015/16. This is lower than the national average (50%) which is the case for all three CCGs: 40% in EHS CCG, 44% in H&R CCG and 44% in HWLH CCG.

In 2015/16, of those eligible who had a health check, just under two thirds (62%) were provided with a Health Action Plan (HAP), 2% declined a HAP and 36% were not provided with a HAP. These proportions are similar to national figures, although there is some local variation by CCG. In H&R CCG 70% are provided with a HAP while only 29% have none. This compares to EHS CCG where less than half of those who have a health check are provided with a HAP (44%) while over half have none (55%).

Table 10: Proportion (%) of eligible adults with a learning disability having a GP health check, 2015/16

	England	East Sussex	EHS CCG	H&R CCG	HWLH CCG
14+ population (mid year estimate 2015)	45,590,582	462,743	160,808	157,189	144,746
Learning Disability: on register all ages	263,588	2,687	888	1,115	765
Number 14+ registered with QOF diagnostic learning disability	209,238	2,507	695	1,067	745
Number 14+ received a health check 2015/16	103,685	1,079	280	474	325
% 14+ received a health check 2015/16	50%	43%	40%	44%	44%
% of 14+ who received a health check who had a Health Action Plan	64%	62%	44%	66%	70%
% of 14+ who received a health check who declined a Health Action Plan	2%	2%	0%	4%	1%
% of 14+ who received a health check but had no Health Action Plan	34%	36%	55%	30%	29%

Source: HSCIC, GPES, ONS and CQRS database, 2016

Health Information

Another key issue is that health information is often inaccessible to people who have low literacy skills, with implications not only for encouraging behaviours that prevent ill-health, (healthy eating, stopping smoking etc.) but also for health screening information, for example invitations for cervical screening¹⁷⁰.

Research suggests the number of women with a learning disability going for cervical screening is between 13% and 47%, compared to between 84% and 89% for the general population¹⁷¹. Health information is frequently written at a level too difficult for people with low literacy skills, which deprives them of a vital source of information about a range of health issues, including about baby care or breastfeeding. At the national Public Health England Learning Disabilities Conference, 2015, people with learning disabilities highlighted the importance of both communication and health checks.¹⁷²

Further Research

The Learning Disabilities Observatory, along with the Health and Social Care Information Centre, are working on the Health and Care Project aiming to get a more detailed understanding of the health of people with learning disabilities in each part of the country, the care they get and how this compares to the health and care of people who don't have learning disabilities. The findings will be reported in 2016.¹⁷³

Cost of Care for CCGs

Transforming Care Programme

Inpatient care

In East Sussex, the annual budget for the Transforming Care programme in 2016/17 was £3,021,000 (to the nearest £1,000). This breaks down per CCG into the following (Table 11):

Table 11: Transforming Care Programme Budget 2016/17

	Annual Budget 2016/17	Annual Forecasted Costs	Difference from Budget
EHS CCG	£771,000	£868,000	£31,000
H&R CCG	£1,673,000	£1,704,000	£98,000
HWLH CCG	£577,000	£711,000	£133,000

* numbers are rounded to the nearest 1,000

Source: Head of Quality, H&R CCG and EHS CCG, 2016

Based on the costs of placements made, the expected forecasted cost of the Transforming Care Programme for 2016/17 is £3,283,000, £262,000 over the budget.

Continuing Health Care

As at July 2016, there are 51 individuals funded by Continuing Health Care (CHC) in East Sussex. Of the 51 CHC cases, 38 packages of care are commissioned directly by the CCGs and 13 are Personal Health Budgets (PHB). This equates to:

- 25 residential placements, inclusive of 2 PHBs
- 4 supported accommodation placements, inclusive of 2 PHBs
- 22 Domiciliary care placements which are a combination of PHBs and directly commissioned care (day care etc).

The average weekly cost of a continuing health care package is between £2,000 to £2,500, with a total commissioned care cost for July 2016 of approximately £611,400 (Table 12). One individual's care package can include more than one placement type. For example, someone could spend the majority of their time in

residential placement but have a PHB for when they go home at weekends/holidays.

Table 12: Overall CHC commissioned care costs for July 2016 per placement type

Placement type	Approximate commissioned care costs for July 2016
Residential	£277,900
Supported Accommodation	£16,100
Domiciliary Care	£42,000
Day care/Respite/School/Other	£105,000
Clinical Services	£15,200
Personal Health Budgets	£155,200
TOTAL	£611,400

Source: NHS Continuing Health Care East Sussex, 2016

Cost of Care for ESCC funded services and placements

Adult Social Care funded Services

Adult Social Care Directly Provided Services include day and residential care, respite and domiciliary care for those living at home, and ESCC in-house services. In East Sussex, the annual budget for ASC Directly Provided Services in 2016/17 is £8,289,000 (to the nearest 1,000). This breaks down per service type into:

Table 13: Adult Social Care LD Directly Provided Services Budget 2016/17

Directly Provided Service	2016/17 Budget (£000's)	2016/17 Forecast spend (£000's)
Day Care/Day Services	2,868	2,868
Residential Care	1,108	1,108
Employment Services	150	150
Other Learning Disability Services	556	556
Respite Services	1,897	1,897
Community Support Services	1,328	1,328
SAILS (Supported Accommodation & Independent Living Solutions)	382	382
TOTAL	£8,289	£8,289

Source: Finance Department, ASC, 2016

Funded placements

The following data is taken from Controcc, the Adult Social Care contract management database, and describes the cost of current placements for East Sussex County Council, looking at the proportions

costing under £1,000 a week, £1,000-£1,999 a week and those over £2,000 a week. According to information from the Adult Social Care contract management system for accommodation placements:

Community/Supported Living : Of the 303 adults with a learning disability who have a supported living or community accommodation placement as at 22nd March 2016, 90% have a care package costing under £1,000 a week (272 placements), 8% (25 individuals) have care packages funded between £1,000 and £1,999 a week, and 2% (6 individuals) are funded for placements in excess of £2,000 a week. The average weekly cost for placements both inside and outside East Sussex is £400.¹⁷⁴

Residential Care: Less than half (45%) of the 480 people in residential accommodation placements (218 individuals) have care packages under £1,000 a week, 49% (236 placements) are funded between £1,000 and £1,999 a week, and 5% (26 individuals) have placements costing over £2,000 a week and would be considered to have higher level needs. The average weekly cost for a residential placement inside East Sussex is £1,070, compared to £1,380 outside East Sussex.¹⁷⁵

Nursing Care: The average weekly cost of a nursing accommodation placement in East Sussex is £930, and outside of East Sussex it is £1,170.¹⁷⁶

Lifestyle

Substance and alcohol misuse

Research shows that rates of smoking among adolescents with mild learning disability are higher than among their peers.¹⁷⁷ Further national evidence suggests that pupils with learning difficulties are significantly more likely to take an illicit substance than those without (14% compared to 11% in 2008/09).¹⁷⁸

In adulthood, research suggests fewer adults with learning disabilities who use learning disability services smoke tobacco or drink alcohol compared to the general population.¹⁷⁹

Diet, exercise and obesity

Less than a quarter of those with learning disabilities take part in regular exercise at the Department of Health recommended minimum level, compared to around half for the general population.¹⁸⁰ The challenges associated with more severe learning disabilities and living in a restricted environment contributes to inactivity.¹⁸¹

Those with a learning disability and a limiting illness are one and a half times more likely to be overweight or obese than those without a limiting illness or a learning disability, with the likelihood of being obese increasing with age.¹⁸²

Obesity is far more prevalent in the learning disabilities population than the general population, with women, people with Down's syndrome, and those living in less restrictive environments such as in their own homes particularly at risk. Underweight is also more common among people with learning disabilities.¹⁸³

Carers

Families and carers

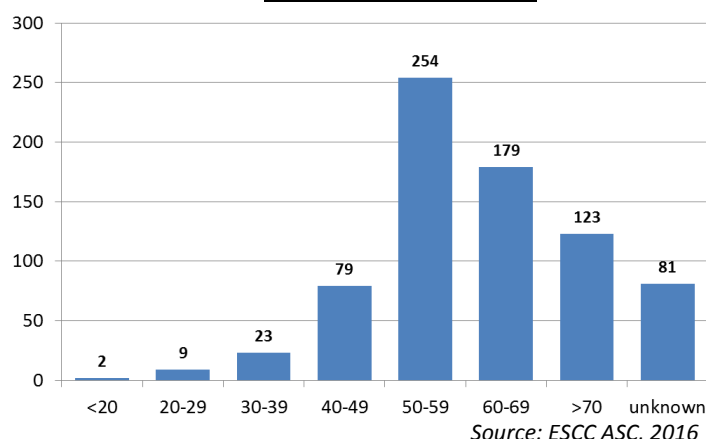
The National Carers Survey 2014/15 highlights that, compared with other carers, carers of people with learning disabilities are on average more likely to have been a carer for a longer period of time, to be living in the same household as the person they care for, and to provide a greater number of hours of care each week.¹⁸⁴ People with high levels of caring responsibility are twice as likely to suffer from poor health as those without caring responsibilities, and are more likely to experience a relationship breakdown.¹⁸⁵

At least half of all adults with a learning disability live in the family home¹⁸⁶, with 29,000 adults with a learning disability in the UK living with parents aged 70 years or older, many of whom are too frail to continue in their caring role. 1 in 4 of these cases nationally has local authority planned alternative housing¹⁸⁷.

As at 16th May 2016, 750 of the carers known to adult social care in East Sussex are supporting 796 adults with a learning disability. A third of the adults being supported are aged between 18 and 25 years. Of those known to be caring for an adult with a learning disability, 73% are female and 25% male (2% not have gender not recorded)¹⁸⁸.

A third (34%) of the known carers of ASC clients who have a learning disability are aged between 50 and 59, while 40% are aged 60 and over (Figure 31).

Figure 31: Age of known carers caring for an adult with a learning disability

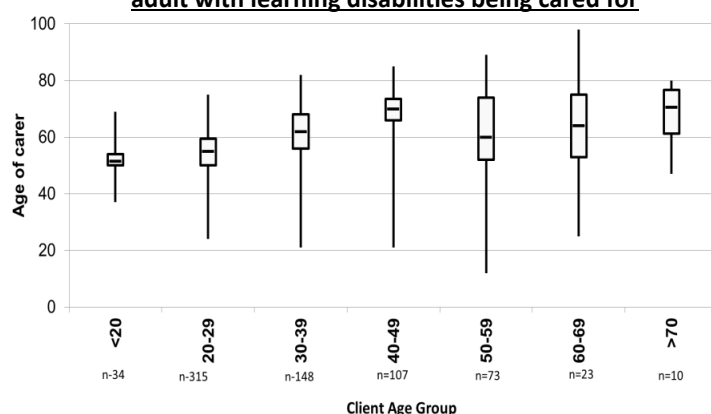


Source: ESCC ASC, 2016

These figures could be higher as the age of 11% of carers is not recorded. 19 carers known to adult social care have a learning disability, 9 of whom are caring for someone who also has a learning disability. 87% of carers known to adult social care (655 carers) are the main carer, although this is likely to be higher as for 11% (82 carers) caring status is not recorded.

Figure 32 shows the minimum and maximum ages of carers for each age group of adults with learning disabilities (lower and upper ends of the vertical lines), with the bold horizontal bar showing the median carer age and the box showing the age range of the middle 50% of carers for each "client" age group. This excludes the 86 people with learning disabilities supported by adult social care for whom both client and carer age is not recorded.

Figure 32: Age difference between carers and the adult with learning disabilities being cared for



Client Age Group

	<20	20-29	30-39	40-49	50-59	60-69	>70
Minimum age	37	24	21	21	12	25	47
Maximum age	69	75	82	85	89	98	80
Median age	51.5	55	62	70	60	64	70.5

Source: Adapted from ESCC ASC, 2016

Figure 9 shows that the median age of carers is approximately 20 years above the age of the cared for person until that person reaches 49 years of age (and the carer is approximately 70 years old). At this point the median age of the carer is likely to be close to that of the cared for person, suggesting a potential change in caring relationships at around this age. This local data supports national evidence outlined above that carers aged 70 years and above are more likely to be unable to continue in their caring role¹⁸⁹.

However, the above local data must be viewed with the caveat that there have been known issues transferring data from the older CareFirst database to a new LAS database, and that sometimes only the main carer has been assessed and the caring roles of other family members or individuals are not recorded.

Primary and Secondary Care Service Use

GP consultations

National evidence¹⁹⁰ suggests that people with learning disabilities visit their GP at a similar frequency to the general population, which does not reflect their greater burden of ill-health.

Inpatient services

National figures from December 2015 give a snapshot of people with learning disabilities who are in hospitals in England. At the end of December there were 2,595 people with learning disabilities in NHS-funded hospital care; however it is likely that the number is greater as 10 Clinical Commissioning Groups failed to provide data. 2,515 of the 2,595 patients identified had been in hospital since the previous month. There were 105 discharges/transfers from hospital but also 80 admissions.¹⁹¹ The recent Learning Disability Census 2015 estimates there are 3,480 people with a learning disability in inpatient units.¹⁹²

In 2012-13 the NHS spent £557 million on inpatients with learning disabilities in mental health hospitals. 83% of the 2,600 people in mental health hospitals were sectioned under the Mental Health Act.¹⁹³ An audit of care services in 2015 found that at June 2014, 2,024 of the 2,601 inpatients had no planned transfer or discharge date, and 1,614 of these had received a clinical decision not to transfer.

In September 2014, local authorities were unaware of the potential transfer to their area on discharge from hospital for 37% of inpatients. At this time 36.5% of services users resided over 50km away from home.¹⁹⁴

The 2014 learning disabilities census identified that as at September 2014 there were more patients with Learning disabilities and/or autism in wards in Hastings and Rother than reside within the CCG area (Table 14):

Table 14: Patients in wards by CCG of residence and CCG of stay

	CCG of patient residence	CCG of ward stay
EHS CCG	5	Under 5
H&R CCG	10	15
HWLH CCG	Under 5	0

(numbers rounded to the nearest five)

Source: HSCIC, 2015

An NHS England report on Transforming Care Programme learning disability bed stock identified there are 222 specialist beds in learning disability inpatient facilities in the South Region for those with LD/challenging behaviour and/or mental health issues and/or ASD. 100 of these specialist beds are in the South East.¹⁹⁵ The Selden Centre is an inpatient service in West Sussex for people with learning disabilities who require expert intensive assessment, intervention and support, and is the local unit for East Sussex. The centre aims to support people back to community living and has a capacity of 10 beds.

As at March 2016 there were 53 people occupying inpatient beds across Sussex:

- 8 people in the Sussex Inpatient Facility
- 18 People out of the Sussex area
- 27 people in NHS commissioned in-patient beds out of area.¹⁹⁶

NHS England specialist commissioning is responsible for commissioning low, medium and high secure hospital placements, as well as inpatient services for children and young people.

Clinical Commissioning Groups (CCGs) are responsible for commissioning locked rehabilitation, assessment and treatment placements. In addition to this, anyone who may have a need for community care services is entitled to a social care assessment when they are discharged from hospital to establish what services they might need. Section 117 of the Mental Health Act imposes a duty on health and social care services to provide aftercare services to certain patients who have been detained under the Mental Health Act.

Aftercare can include almost anything arising from or related to the person's mental disorder that helps someone live in the community, for example, help with specialised accommodation, social care support,

day centre facilities or recreational activities.¹⁹⁷

East Sussex is funding 6 individuals who continue to receive care and treatment; three in out of areas specialist hospitals and three in the West Sussex assessment and treatment centre.

Hospital admissions

National research looking at Ambulatory care sensitive conditions (ACSCs), (that is conditions which, given effective management at the primary care level, should not normally result in hospital admission) for people with learning disabilities in the UK looked at admissions, bed use and prominent cause of admissions using Hospital Episode statistics (HES) between 2005-2009. This should be interpreted with slight caution due to problems identifying people with learning disabilities (results are described as an underestimate for this reason), and a lack of age/sex breakdown for the estimated learning disabled population at this time.¹⁹⁸

Looking at 3.5 million episodes of hospital care, ACSCs accounted for 8% of episodes and 14% of all bed days for people without learning disabilities, compared to 16% episodes and 24% of bed days for people with learning disabilities. Using national prevalence estimates for the adult population of people with a learning disability, it was suggested the crude rate of emergency admissions for ACSC's was 76 per 1,000 adults with a learning disability, compared to approximately 15 per 1,000 people without a learning disability. Admissions for people with learning disability associated conditions lasted on average 5.8 days per admission compared to 3.7 days for admissions for people without a learning disability.

Emergency admission numbers for people with learning disabilities rose with age-group in early adulthood, peaking in 35-44 year olds, (21% of all admissions), before falling steadily. For people without a learning disability there was a sharp rise in emergency admissions for ACSCs in the oldest age groups.¹⁹⁹

ACSC admissions attributed to convulsions and epilepsy was four times greater for people with learning disabilities aged 18 to 64 years than for those without learning disabilities, with emergency admission for this condition accounting for 41% of all emergency ACSC admissions (an average of 6,000 admissions annually), and 27% of bed days (28,000 annually). This is of particular importance because of the key role of epilepsy and convulsions as a cause of death in people with learning disabilities.²⁰⁰ Emergency admissions for this indicate ineffective epileptic control and/or lack of adequate rescue medication plans.²⁰¹

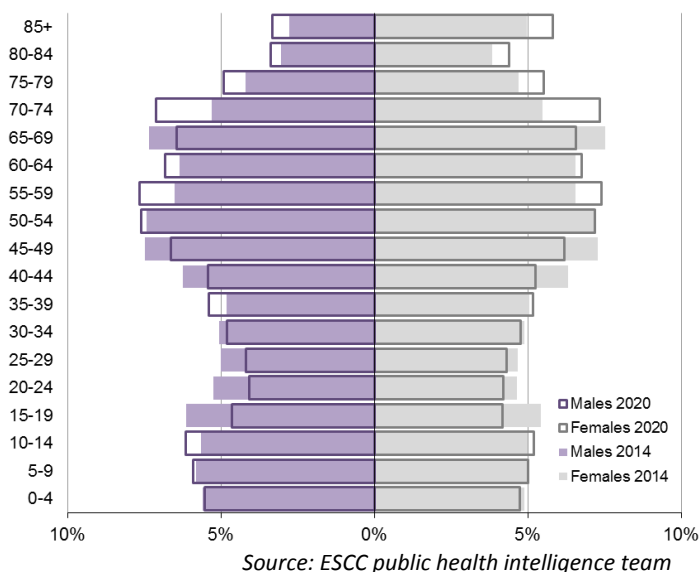
A small number of other conditions appear to have particular significance for people with learning disabilities, including diabetes, constipation and influenza/pneumonia. Angina, chronic obstructive pulmonary disease and congestive heart failure emerged as proportionately important causes of emergency ACSC admissions for people without learning disabilities, but were less prominent for people with learning disabilities.²⁰²

Generally hospital data is available by length of stay, frequency of admission, age, and reason for admission, including certain codes attributed to types of learning disability for people with an East Sussex postcode. However, there are issues of accuracy and data completeness as not everyone with a learning disability is coded as such at hospital admission, and some admissions give learning disability as the reason for admission rather than a specific purpose such as an operation or treatment for illness. This information is not currently useful for service planning but data about reasons for and frequency of admission could potentially be useful as a measure of access if the issues outlined above are addressed.

Future Need

Local population projections to 2020 (Figure 33) suggest that over the next six years the population of East Sussex will increase by approximately 1.8% from 540,000 to 550,000.²⁰³

Figure 33: 2014 East Sussex population and 2020 projections



The numbers of people with learning disabilities in the population is influenced by a range of demographic factors which influence incidence (number of new

cases) and prevalence (numbers of people increasing from improved life expectancy). National modelling suggests sustained growth in the *need* for social care services for adults with learning disabilities between 2011 and 2026, with estimated average annual increases varying from 1.2% to 5.1% (average 3.2%).²⁰⁴

This differs from the *demand* for services which is likely to outstrip changes in need due to a variety of factors combining to reduce the capacity of informal support networks to provide care, for example: increases in lone parent families; more women in work; increasing life expectancy of people with learning disabilities and changing expectations of people's right to live independently.²⁰⁵

Demand can also be generated by the way in which health and social care systems operate. For example, when issues are not dealt with at an early stage or where systems are complex to navigate, people may be forced into more regular and high demand contact with services than is necessary, and the more reliant on these services people become, the more their demand for them increases.²⁰⁶

With the exception of Learning Disability services there is evidence that the numbers of people receiving state support from councils in social care is declining.²⁰⁷ Current demand for services for people with learning disabilities is also increasing, and demographic trends suggest that this growth is set to continue over the next 15 years.²⁰⁸

The most widely cited estimates of future demand and need for learning disability services are those from a project conducted by Emerson and Glover at Improving Health and Lives (IHaL): Learning Disabilities Observatory on behalf of Mencap and the Department of Health.²⁰⁹ Previous estimates have suggested that the extent and pattern of need for social care services for adults with learning disabilities in England is likely to change due to:

- Decreasing mortality among people with learning disabilities, especially in older age ranges and among children with severe and complex needs;
- The impact of changes in fertility over the past two decades in the general population;
- The ageing of the 'baby boomers', among whom there appears to be an increased incidence of learning disabilities.²¹⁰

It is predicted that these demographic changes will result in a significant increase in the numbers of older people with learning disabilities and young people with complex needs and learning disabilities requiring support.

The IHaL model estimating future need involved the following stages:

1. Adjusting school census data on the number of children with SEN associated with learning disability in England for the effects of mortality to estimate those who would reach the age of 18.
2. Deriving upper, middle and lower estimates of the percentage of these children likely to become eligible for adult social care services
3. Using HSCIC information from the Information Centre for Health and Social Care and information extracted from a number of learning disability case registers to estimate the number and age of adults using social care services at present, and then adjusting this for the expected effects of mortality over future years.
4. Combining the above data with estimated inflows from child services to estimate net changes in need.

The IHaL research estimates that:

- Approximately 25% of new entrants to adult social care with learning disabilities will belong to minority ethnic communities
- Approximately one in three new entrants to adult social care will come from a home in which the child is eligible for Free School Meals (nationally one in six children in this age range are eligible for Free School Meals)
- By 2030 the number of adults aged 70+ using social care services for people with learning disabilities will more than double²¹¹.

The following section uses the IHaL modelling to estimate future need for services for people with learning disabilities in East Sussex.

Future need in East Sussex

The IHaL model provides national level estimates of for new entrants to adult learning disability services until 2030. These estimates have been calculated based on the prevalence of special educational needs associated with learning disabilities in school age children, taken from the school census. The figures were then adjusted to take account of mortality rates and combined with existing adult care services figures. Estimates were calculated using three levels of social care access criteria:

1. Adult care services will only be made available to people with critical or substantial need (lower estimate)
2. Adult care services will only be available to people with critical or substantial needs, in addition to around 50% of people with moderate needs (Middle estimate)
3. Adult care services will be available to any with

critical, substantial or moderate need (upper estimate)

Based on the above, the projection estimated that there will be an average annual growth in access to adult care of between 1.2% and 5.1% between 2011 and 2026, an average of 3.2%.

Future service use

Figures 34, 35 and 36 model the IHaL projections to the East Sussex population. For all estimates the annual percentage growth rate slows from 2011 to 2018/19 at which point it stabilises before beginning to gradually increase again. This pattern reflects changes in birth rates over the last two decades. Appendix A outlines the modelled data estimates of adults with learning disabilities in East Sussex predicted to use social care services over the next ten years.

Figure 34: Estimates of the number of learning disabled adults with critical and substantial needs using social care services

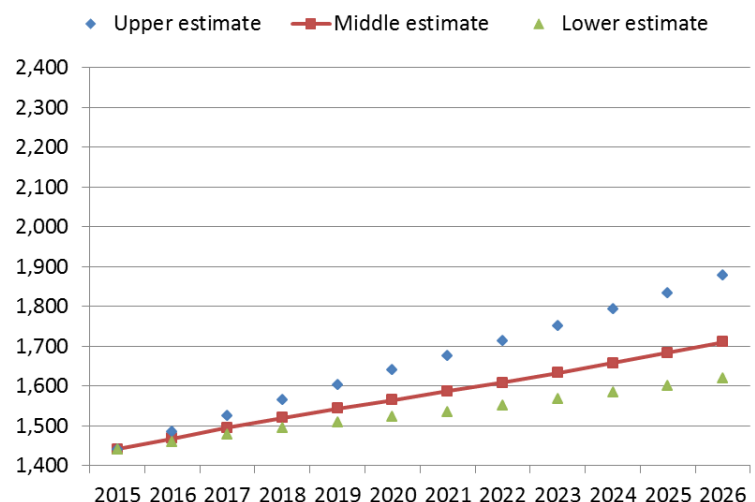
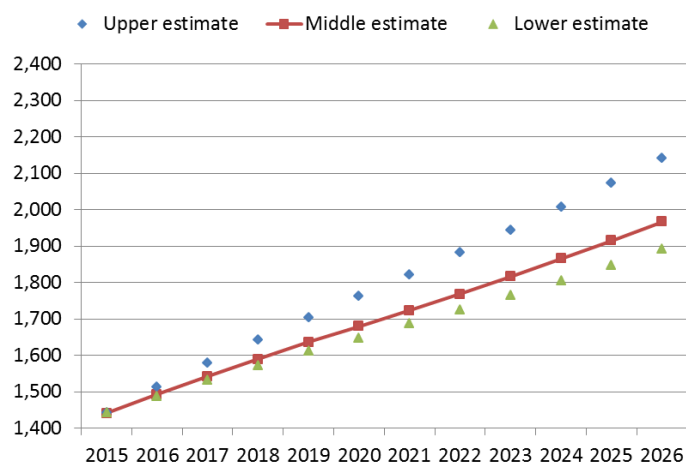


Figure 34 indicates an estimated increase in provision of support of 270 adults with learning disabilities with critical and substantial needs only over the next 10 years. The model identifies an upper range estimate of 437 and a lower range estimate of 179.

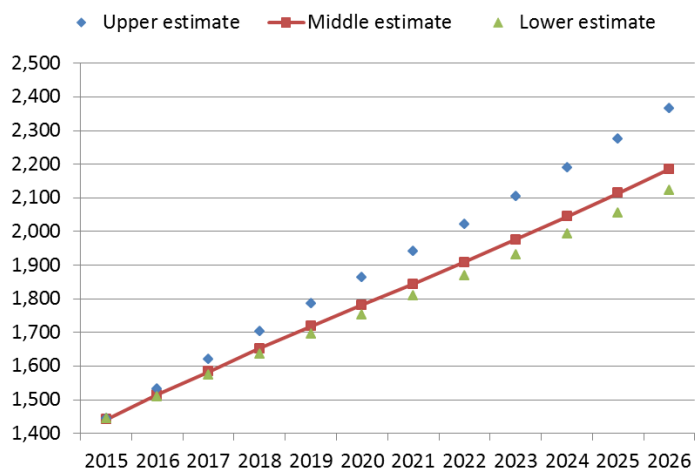
For those with critical and substantial needs and 50% of those with moderate needs, figure 35 suggests an estimated increase in provision of support of 527 adults with learning disabilities over the next 10 years, within a range of 450-700.

Figure 35: Estimates of the number of learning disabled adults with critical, substantial and 50% of moderate needs using social care services



If support was given to those with critical, substantial and moderate needs over the next ten years, there would be an estimated increase of 745 adults with learning disabilities using social care services, with an upper estimate of 922 and a lower estimate of 679 (Figure 36).

Figure 36: Estimates of the number of learning disabled adults with critical, substantial and moderate needs using social care services



These predictions must be read with caution as they are nationally-based estimates of 'need' rather than 'demand', with changes in demand likely to outstrip changes in need due to several factors combining to reduce the capacity of informal support networks (primarily unpaid labour of women) to provide care.

Future projections of older people needing social care support

The IHaL modelling²¹² predicts a 14% increase in numbers of older people aged 50+ using social care

services from 2011 to 2030, or around 0.7% a year. Although proportionate growth is much higher in the older age bands, there are fewer numbers in these age groups, and therefore smaller growth in actual numbers of people. If this is applied to our current population of people over 50 years old with learning disabilities who are in receipt of social care support (482 people), this suggests an increase of 68 people to 550 individuals aged over 50 needing services in 2030.

However, this masks marked variation by age group, with estimated annual growth rates of 0.2% of 50-59 year olds, 3.2 for 60-69 year olds, 4.2% for 70-79 year olds and 5.8% for those over 80 years. Taking these annual growth rates and applying them to our current cohort of adults with learning disabilities receiving social care services, Table 15 estimates future service use of older people over the next ten years.

Table 15: Estimates of the number of older adults with learning disabilities using social care services

	50-59 (0.2%)	60-69 (3.2%)	70-79 (4.2%)	80 (5.8%)
2015	250	164	64	32
2016	251	169	67	34
2017	251	175	69	36
2018	252	180	72	38
2019	252	186	75	40
2020	253	192	79	42
2021	253	198	82	45
2022	254	204	85	47
2023	254	211	89	50
2024	255	218	93	53
2025	255	225	97	56
2026	256	232	101	59
% growth 2015-2026	2%	42%	58%	84%

Source: modelled from Emerson and Glover, 2012

Table 15 shows a projected 58% increase in the number of adults aged 70-79 and an 84% increase in those aged 80+ with a learning disability using social care services over the next ten years. However, this is based on national population estimates, and it is possible that this number would be higher in East Sussex due to the fact that the county has the second highest 75+ and 85+ populations in the country. The number of older people requiring services is of critical importance for planning housing and care needs: increasing life expectancy for people with learning

disabilities means many will outlive their parents, who may be principal carers for them. Diseases such as dementia, which is more than three times as common in the learning disabilities population for those over 65 than the general population, will impact on people's needs, as will some other common health conditions.

Downs Syndrome

Based on evidence indicating a prevalence rate of 6.25 per 10,000 population²¹³, it is estimated that there are approximately 190 adults with Downs Syndrome in East Sussex.²¹⁴ Overall this figure is not predicted to change significantly, although small reductions in most age groups are offset by a potential increase in the 55-64 age group. However, these differences still concern relatively small numbers and should be treated with caution considering suggestions that the average life expectancy for people with Downs Syndrome is 60.²¹⁵

Challenging behaviour

There are an estimated 135 people aged 18-64 with a learning disability, predicted to display seriously challenging behaviour, based on a prevalence of 0.045% of the population aged 5 or older²¹⁶. This means challenging behaviours are shown by approximately 10%-15% of people with learning disabilities, with age-specific prevalence peaking between ages 20 and 49.²¹⁷ Not all these people will have a moderate, severe or profound disability and so not all of them will be in receipt of learning disability services. Many will be at risk of offending and will have come into contact with the criminal justice system, substance misuse or mental health services.

Autistic Spectrum Disorders (ASD)

It is estimated that approximately 2,640 males and 300 females in East Sussex currently have ASD. This is predicted to rise by approximately 30 males over the next five years, although the number of females with ASD remains similar in 2020. As with other forms of learning disability, the greatest predicted rise is among the 55-64 age group, while the most significant decrease is predicted in the 18-24 year age group.

Reducing Inequalities

A 2012 report for the national Learning Disabilities Observatory *Health Inequalities & People with Learning Disabilities in the UK*²¹⁸ (Table 16) identified a number of ways to reduce inequalities among those with learning disabilities:

Table 16: Reducing inequalities amongst people with learning disabilities

	Solution
1	Reduce the exposure of people with learning disabilities to adverse social determinants: poverty, poor housing, unemployment, social disconnectedness and discrimination
2	Improve the early identification of illness through annual health checks and cervical and breast screening
3	Enhance the health literacy of people who play a critical role in promoting healthy lifestyles: e.g. family and carers
4	Enhance healthcare workers' knowledge and skills for working with people with learning disabilities
5	Make 'reasonable adjustments' in all areas of health promotion and healthcare, and act within legal frameworks of the Equality Act 2010 and the Mental Capacity Act 2005 (e.g. more accessible information and longer appointments)
6	Build a more robust evidence-base of the determinants of health inequalities among people with learning disabilities, and effectiveness of interventions to reduce them. Monitor progress towards the elimination of these health inequalities

Further to this, a national evidence and best practice review funded by the Economic and Social Research Council and Local Government Association²¹⁹ outlined core themes central to provision for growing need:

- Look **at models and approaches used elsewhere** for best practice²²⁰
- Take a **whole systems approach** working across all services for those with learning disabilities^{221,222}
- As well as working across traditional service or budget boundaries **services must be flexible and fast responding**
- **Review commissioning arrangements** (an area where large savings have been identified)
- **Invest in prevention** (e.g. intensive individual work) where the person with a learning disability is exhibiting challenging behaviour
- **Tackle the context for inter-related health issues** such as pain or untreated conditions which may be causing more challenging behaviour²²³
- **Avoid residential placements** and certain elements of these²²⁴
- **Invest in carers, support networks**, initiatives supporting independent living, and community
- **Train all staff** to make appropriate referrals and work with people with learning disabilities to plan the most effective care and crisis management
- **Focus on prevention in the broader population** by tackling inequalities, poverty and social determinants of health. Good maternal and neonatal services are also important²²⁵
- Prevent the escalation of needs becoming more challenging and costly to meet through **demand management techniques** to manage service provision in the context of declining budgets.

Appendix A: Modelled estimates of future service need for adults with learning disabilities in East Sussex

http://www.improvinghealthandlives.org.uk/uploads/doc/vid_10673_IHaL2011-05FutureNeed.pdf

Table 1: Estimated Number of Adults with Learning Disabilities Using Social Care Services (Critical & Substantial Needs Only)

	Number of eligible users			Estimated % annual growth		
	Upper estimate	Middle estimate	Lower estimate	Upper estimate	Middle estimate	Lower estimate
2015	1,441	1,441	1,441			
2016	1,484	1,468	1,460	3	1.9	1.3
2017	1,526	1,495	1,477	2.8	1.8	1.2
2018	1,565	1,520	1,493	2.6	1.7	1.1
2019	1,603	1,543	1,508	2.4	1.5	1
2020	1,640	1,565	1,522	2.3	1.4	0.9
2021	1,676	1,587	1,536	2.2	1.4	0.9
2022	1,713	1,609	1,551	2.2	1.4	1
2023	1,752	1,633	1,567	2.3	1.5	1
2024	1,793	1,657	1,584	2.3	1.5	1.1
2025	1,834	1,684	1,601	2.3	1.6	1.1
2026	1,878	1,711	1,620	2.4	1.6	1.2

Table 2: Estimated Number of Adults with Learning Disabilities Using Social Care Services (Critical & Substantial and 50% of Moderate Needs)

	Number of eligible users			Estimated % annual growth		
	Upper estimate	Middle estimate	Lower estimate	Upper estimate	Middle estimate	Lower estimate
2015	1,441	1,441	1,441			
2016	1,510	1,493	1,486	4.8	3.6	3.1
2017	1,577	1,542	1,529	4.4	3.3	2.9
2018	1,641	1,590	1,570	4.1	3.1	2.7
2019	1,702	1,636	1,609	3.7	2.9	2.5
2020	1,762	1,680	1,646	3.5	2.7	2.3
2021	1,820	1,724	1,684	3.3	2.6	2.3
2022	1,880	1,769	1,723	3.3	2.6	2.3
2023	1,942	1,816	1,763	3.3	2.7	2.3
2024	2,006	1,866	1,803	3.3	2.7	2.3
2025	2,072	1,916	1,846	3.3	2.7	2.4
2026	2,140	1,968	1,891	3.3	2.7	2.4

Table 3: Estimated Number of Adults with Learning Disabilities Using Social Care Services
(Critical & Substantial and Moderate Needs)

	Number of eligible users			Estimated % annual growth		
	Upper estimate	Middle estimate	Lower estimate	Upper estimate	Middle estimate	Lower estimate
2015	1,441	1,441	1,441			
2016	1,530	1,514	1,507	6.2	5.1	4.6
2017	1,618	1,584	1,571	5.7	4.6	4.2
2018	1,702	1,652	1,633	5.2	4.3	4
2019	1,783	1,718	1,692	4.8	4	3.6
2020	1,862	1,782	1,750	4.4	3.7	3.4
2021	1,940	1,844	1,807	4.2	3.5	3.3
2022	2,020	1,909	1,867	4.1	3.5	3.3
2023	2,102	1,976	1,929	4.1	3.5	3.3
2024	2,186	2,045	1,990	4	3.5	3.2
2025	2,274	2,114	2,054	4	3.4	3.2
2026	2,363	2,186	2,120	3.9	3.4	3.2

- 1 Emerson E, Heslop P. A Working Definition of Learning Disabilities. Durham: Improving Health & Lives: Learning Disabilities Observatory, 2010.
- 2 Enderby, P. et al (2009) Resource Manual for Commissioning and Planning Services for SLCN. Royal College of Speech and Language Therapists
- 3 Department of Health (2001) Valuing People: A New Strategy for Learning Disability for the 21st Century
- 4 British Institute of Learning Disabilities (2011) Factsheet: Learning Disabilities.
- 5 Enderby, P. et al (2009) Resource Manual for Commissioning and Planning Services for SLCN. Royal College of Speech and Language Therapists
- 6 Emerson and Heslop (2010) A working definition of learning disabilities. IHaL Learning Disabilities Observatory
http://www.nepho.org.uk/uploads/doc/vid_7446_2010-01WorkingDefinition.pdf
- 7 Department for Education and Skills (2005) Data Collection by Type of Special Educational Need
- 8 Kelly A. 2002. Working with adults with a learning disability. Speechmark. Oxon
- 9 British Institute of Learning Disabilities (2011) Factsheet: Learning Disabilities
- 10 National Audit Office (2015) Care services for people with learning disabilities and challenging behaviour
- 11 Emerson, E. Baines, S. (2010) Health Inequalities & People with Learning Disabilities in the UK, IHaL.
- 12 Local Government Knowledge Navigator (2014) What Councils Need to Know about People with Learning Disabilities. Dr Paula Black
- 13 www.improvinghealthandlives.org.uk/publications/1241/People-with-Learning-Disabilities-in-England-2012
- 14 National Institute for Health and Clinical Excellence (Sept 2011) Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum NICE clinical guideline 128 guidance.nice.org.uk/cg128
- 15 NHS Choices (March 2016) What is learning disability
<http://www.nhs.uk/Livewell/Childrenwithlearningdisability/Pages/Whatislearningdisability.aspx>
- 16 NHS Choices (March 2016) What is learning disability
<http://www.nhs.uk/Livewell/Childrenwithlearningdisability/Pages/Whatislearningdisability.aspx>
- 17 Mencap (2016) About Learning Disabilities - Causes
- 18 Richardson, S.A., & Koller, H. (1996). Twenty Two Years: Causes and Consequences of Mental Retardation. Cambridge: Harvard University Press
- 19 Emerson E, Hatton C, Robertson J, Roberts H, Baines S, Evison F, et al. People with Learning Disabilities in England: 2012. Durham: Improving Health & Lives: Learning Disabilities Observatory, 2012
- 20 Department of Health (2009) Valuing People Now: a new three-year strategy for people with learning disabilities 'Making it happen for everyone'
- 21 Health & Social Care Information Centre (October 2016) Disease Prevalence: Quality and Outcomes Framework (QOF) for April 2015 - March 2016, England
- 22 ESCC (October 2016) 2015-based ESCC population projections (dwelling-led)
- 23 ONS (2015) statistical bulletin: Annual Mid-year population estimates: 2014
<http://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/annualmidyearpopulationestimates/2015-06-25>
- 24 ESIF (2015) population estimates...in brief
- 25 British Institute of Learning Disabilities (2011) Factsheet: learning disabilities.
- 26 Emerson E, Hatton C, Robertson J, Roberts H, Baines S, Evison F, et al. People with Learning Disabilities in England: 2012. Durham: Improving Health & Lives: Learning Disabilities Observatory, 2012
- 27 The NHS Information Centre, Community and Mental Health Team, Brugha, T. et al (2012). *Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey*. Leeds: NHS Information Centre for Health and Social Care
- 28 ONS (2015) Mid-2014 Population Estimates for Clinical Commissioning Groups (CCGs) in England by Single Year of Age
- 29 http://www.bacch.org.uk/publications/other_service_improvement.php
- 30 Baron-Cohen S et al. Prevalence of autism-spectrum conditions: UK school-based population study. The British Journal of Psychiatry (2009) 194: 500-509
- 31 Emerson, E. and Baines, S. (2010) *The estimated prevalence of autism among adults with learning disabilities in England*. Stockton-on-Tees: Improving Health and Lives.
- 32 The NHS Information Centre, Community and Mental Health Team, Brugha, T. et al (2012). *Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey*. Leeds: NHS Information Centre for Health and Social Care
- 33 The National Autistic Society, cited by PANSI, accessed March 2016.
- 34 Public Health England (2015) Learning Disability Profiles
<http://fingertips.phe.org.uk/profile/learning-disabilities>
- 35 Emerson E, Hatton C, Robertson J, Roberts H, Baines S, Evison F, et al. People with Learning Disabilities in England: 2012. Durham: Improving Health & Lives: Learning Disabilities Observatory, 2012
- 36 Emerson E. Household deprivation, neighbourhood deprivation, ethnicity and the prevalence of intellectual and developmental disabilities Journal of Epidemiology and Community Health 2012;66:218-24.
- 37 ONS (2015) Table SAPE17DT5: Mid-2014 Population Estimates for Clinical Commissioning Groups in England, by Single Year of Age and Sex
- 38 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/446720/SFR25-2015_TABLES_LA.xlsx
- 39 Public Health England (2015) Learning Disability Profiles
<http://fingertips.phe.org.uk/profile/learning-disabilities>
- 40 ESCC ASC Performance Team (2016)
- 41 PHE (2014) Joint Strategic Needs Assessments 2014: How well do they address the needs of people with learning disabilities?
- 42 National Adult Social Care Intelligence Service (accessed 04/08/16) RAP:P1 Number of clients receiving services during the period, provided or commissioned by the CSSR, by primary client type, service type, and age group.
- 43 NICE (Feb 2016) Transition from Children's to adult's services for young people using health or social care services. NICE guideline NG43
- 44 Maughan, B., Collishaw, S., & Pickles, A. (1999). Mild mental retardation: Psychosocial functioning in adulthood. Psychological Medicine 29, 351-366. See also, Fujiura, G. (2003). Continuum of intellectual disability: Demographic evidence for the 'Forgotten Generation'. Mental Retardation 41, 420-429.
- 45 DfE (July 2015) Special Educational Needs in England: January 2015. ONS
- 46 This refers to pupils whose domicile address is in East Sussex but who could be attending any type of educational provision both in and out of county.
- 47 Public Health England (2015) Learning Disability Profiles
<http://fingertips.phe.org.uk/profile/learning-disabilities>
- 48 Public Health England (2015) Learning Disability Profiles
<http://fingertips.phe.org.uk/profile/learning-disabilities>
- 49 DfE (July 2015) Special Educational Needs in England: January 2015. ONS
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/446720/SFR25-2015_TABLES_LA.xlsx
- 50 Public Health England (2015) Learning Disability Profiles
<http://fingertips.phe.org.uk/profile/learning-disabilities>
- 51 ESCC CDS Data, research and information management team (2016) Data taken from Core pupil database (SEN module)
- 52 ESCC CDS Data, research and information management team (2016) Data taken from January 2015 census

- 53 ESCC CDS Data, research and information management team (March 2016) Local authority core pupil database (sen module)
- 54 ESCC CDS Data, research and information management team (March 2016) School Census Data 2015
- 55 ESCC CDS Data, research and information management team (March 2016) School Census Data 2015
- 56 Draft Transforming Care Plan (data accessed March 2016)
- 57 Institute for Public Policy Research (2007), Disability 2020: Opportunities for the full and equal citizenship of disabled people in Britain in 2020, London: IPPR
- 58 http://www.improvinghealthandlives.org.uk/securefiles/131021_1728/IHAL2012-04PWLD2011.pdf page 45
- 59 ESCC Research and Information Team (2015) ESIF: Indices of Deprivation 2015
- 60 ESCC Children's Department (March 2016) School Census Data 2015
- 61 Department for Education (Oct 2012) Children with special educational needs: an analysis - 2012
- 62 Department for Education (Oct 2012) Children with special educational needs: an analysis - 2012
- 63 ESCC Data research and information team analysis (2016)
- 64 ESCC Integrated continuing health care team, March 2016
- 65 McGill et al, 2006, cited by Lombard, D. (2009) Meeting the Specific Needs of Children with Disabilities. CommunityCare.co.uk.
- 66 http://www.improvinghealthandlives.org.uk/gsf.php5?f=17280&f_v=18581 Page 41
- 67 Emerson E, Hatton C, Robertson J, Roberts H, Baines S, Evison F, et al. People with Learning Disabilities in England: 2012. Durham: Improving Health & Lives: Learning Disabilities Observatory, 2012
- 68 Kent Community Health NHS Foundation Trust (2015) Annual Report Kent Community Health Foundation Trust provision for looked after children and young people East Sussex, October 2014 to August 2015
- 69 Department for Children, Schools and Families (2008) Transition: moving on well. A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability.
- 70 National Transition Support Team Information Sheet: The Transition Support Programme: Improving support for disabled young people in transition to adulthood
- 71 Bloom R, Kuhlthau K, Van Cleave J, et al. (2012) Health care transition for youth with special health care needs
- 72 NICE (Feb 2016) Transition from Children's to adult's services for young people using health or social care services. NICE guideline NG43
- 73 Department for Children, Schools and Families (2007) A transition guide for all services: key information for professionals about the transition process for disabled young people.
- 74 University of York (2013) Transition to adult services and adulthood for young people with autistic spectrum conditions SPRU
- 75 Kelly B (2013) Don't box me in: disability and transitions to young adult life
- 76 Transition Information Network (2007) cited by Littlewood, B., Curran, B., Dixon, N., Byers, C., Fearn, D. (2007) A Needs Analysis for Children and Young People with Learning Difficulties and/or Physical Disabilities in Hertfordshire. The Centre for Community Research. University of Hertfordshire
- 77 ESCC Transition Service Manager March 2016
- 78 ESCC Transition Service Manager March 2016
- 79 ESCC Transition Team 2016
- 80 Strategic Commissioning Learning Disability (provided May 2016) Criteria for access to Learning Disability Assessment Services
- 81 Sussex Transforming Care Partnerships Plan for people with learning disability and/or autism (May 2016)
- 82 Sussex Transforming Care Partnerships Plan for people with learning disability and/or autism (May 2016)
- 83 Care Quality Commission (2015) Statement on CQC's roles and responsibilities for safeguarding children and adults
- 84 Public Health England (2015) Learning Disability Profiles
- 85 ESCC (2014) Policy: Self Directed Support. V2
- 86 Public Health England (2015) Learning Disabilities Profiles
- 87 ESCC Adult Social Care Performance and Engagement Unit (2016)
- 88 ESCC (2015) Adult social care learning disabilities equality summary
- 89 ESCC Adult Social Care Performance and Engagement Unit (2016)
- 90 <https://nascis.hscic.gov.uk/Tools/Olap/Rap/RapP1.aspx>
- 91 ESCC Adult Social Care Performance and Engagement Unit (2016)
- 92 http://www.improvinghealthandlives.org.uk/gsf.php5?f=17280&f_v=18581 p7
- 93 Fombonne, E., Quirke, S. and Hagen, A. (2011). Epidemiology of pervasive developmental disorders. In Amaral D.G., Dawson G. and Geschwind D.H. eds. (2011) *Autism spectrum disorders*. New York: Oxford University Press, pp. 90 – 111.
- 94 Gould, J. and Ashton-Smith, J. (2011) Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum. *Good Autism Practice*, 12 (1), pp. 34-41.
- 95 http://www.improvinghealthandlives.org.uk/gsf.php5?f=17280&f_v=18581 Page 47
- 96 ESCC Adult Social Care Performance and Engagement Unit (2016)
- 97 Booth T (2000). Parents with learning difficulties, child protection and the courts. *Representing Children* 13, 175-188.
- 98 McConnell D, Mayes R and Llewellyn G (2008). Women with intellectual disability at risk of adverse pregnancy and birth outcomes. *Journal of Intellectual Disability Research* 52 (6) 529-535.
- 99 Emerson E, Malam S, Davies I and Spencer K (2005). Adults with learning difficulties in England 2003/4.
- 100 Department of Health (2009) Valuing People Now: a new three-year strategy for people with learning disabilities. London: DH.
- 101 Guinea S (2001). Parents with a learning disability and their views on support received: A preliminary study. *Journal of Learning Disabilities*, 5, 43-56.
- 102 IASSID (2008). Parents labelled with intellectual disability: Position of the IASSID SIRG on parents and parenting with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21, 296-307.
- 103 Mencap (2011) Inclusive support for parents with a learning disability. A project funded by the Department of Health
- 104 Wade C, Llewellyn G and Matthews J (2008). Review of parent training interventions for parents with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 21, 351-366.
- 105 Feldman MA (2002). Parents with intellectual disabilities and their children: impediments and supports. *Ethical issues in Sexuality of People with Intellectual Disabilities*. NADD Press, Kingston, NY
- 106 Aunos M, Feldman M and Goupil G (2008). Mothering with intellectual disabilities: Relationships between social support, health and well-being, parenting and child behaviour outcomes. *Journal of Applied Research in Intellectual Disabilities*, 21, 320-33
- 107 McConnell D, Mayes R and Llewellyn G (2008). Women with intellectual disability at risk of adverse pregnancy and birth outcomes. *Journal of Intellectual Disability Research* 52 (6) 529-535.
- 108 Feldman MA (2002). Parents with intellectual disabilities and their children: impediments and supports. *Ethical issues in Sexuality of People with Intellectual Disabilities*. NADD Press, Kingston, NY
- 109 Gibbs SM, Brown MJ, Muir WJ (2008). The experiences of adults with intellectual disabilities and their carers in general hospitals: a focus group study. *Journal of Intellectual Disability Research*, 52 (12), 1061-1077.
- 110 McConnell D, Llewellyn G, Mayes R, Russo D and Honey A (2003). Developmental profiles of children born to mothers with intellectual disability. *Journal of Intellectual and Developmental Disability*, 28, 122-134.
- 111 McConnell D, Mayes R and Llewellyn G (2008). Pre-partum distress in women with intellectual disabilities. *Journal of intellectual and Developmental Disability*, June 33 (2), 177-183.
- 112 Mencap (2011) Inclusive support for parents with a learning disability. A project funded by the Department of Health
- 113 Phillips A, Morrison J and Davis RW (2004). General practitioners' educational needs intellectual disability health. *Journal of Intellectual Disability Research*, 48, 142-9.

- 114 Royal College of Nursing (2016) Connect for change: an update on learning disability services in England
- 115 National Audit Office (2015) Care services for people with learning disabilities and challenging behaviour
- 116 ESCC ASC Strategy, Commissioning and Supply Management (March 2016) Control provider management database
- 117 Emerson and Baines (2010) Health Inequalities and people with learning disabilities in the UK: 2010. IHaL and Department of Health
- 118 ESCC Research and Information Team (2015) ESIF: Indices of Deprivation 2015
- 119 Emerson E and Hatton C. 2008. Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England. Centre for Disability Research.
- 120 Redman, S et al (2009). *Don't Write Me Off: Make the system fair for people with autism*. London: The National Autistic Society, p8
- 121 Public Health England (2015) Learning Disabilities Profiles
- 122 ESCC (May 2015) Adult social care 2014-15 summary of performance
- 123 Shelter (2014) 'Settled housing offers'
- 124 http://www.datadictionary.nhs.uk/data_dictionary/attributes/s/ses/settled_accommodation_indicator_de.asp?shownav=1
- 125 Public Health England (2015) Learning Disabilities Profiles
- 126 ESCC Adult Social Care Performance and Engagement Unit (2016)
- 127 Foundation for People with Learning Disabilities (2012) People with learning disabilities and the criminal justice system
- 128 HMP Prison Lewes (2016) HMP Education department data
- 129 Public Health England (2015) Learning Disability Profiles <http://fingertips.phe.org.uk/profile/learning-disabilities>
- 130 ESCC ASC Performance and Engagement Unit (2016)
- 131 Heslop et al (2013) Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) Final report <http://www.bris.ac.uk/cipold/fullfinalreport.pdf>
- 132 http://www.improvinghealthandlives.org.uk/uploads/doc/vid_9_033_IHAL2010-06%20Mortality.pdf
- 133 http://www.improvinghealthandlives.org.uk/uploads/doc/vid_9_033_IHAL2010-06%20Mortality.pdf
- 134 <http://www.improvinghealthandlives.org.uk/gsf.php5?f=16453&fv=17942>
- 135 Public Health England (2016) Health and Care for people with learning disabilities. Gyles Glover IHaL conference presentation
- 136 Arron K, Oliver C, Moss J, Berg K, Burbidge C. The prevalence and phenomenology of self-injurious and aggressive behaviour in genetic syndromes. *Journal of Intellectual Disability Research* 2011;55:109-20
- 137 http://www.rnib.org.uk/aboutus/Research/reports/2011/Learn_dis_small_res.pdf
- 138 McCarthy M. 'I have the jab so I can't be blamed for getting pregnant': Contraception and women with learning disabilities. *Women's Studies International Forum* 2009;32:198-208.
- 139 Servais L. Sexual health care in persons with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews* 2006;12:48-56.
- 140 McCarthy M. Exercising choice and control - women with learning disabilities and contraception. *British Journal of Learning Disabilities* 2010;38:293-302
- 141 McCarthy M. 'I have the jab so I can't be blamed for getting pregnant': Contraception and women with learning disabilities. *Women's Studies International Forum* 2009;32:198-208.
- 142 Schupf N, Zigman W, Kapell D, Lee JH, Kline J, Levin B. Early menopause in women with Down's syndrome. *Journal of Intellectual Disability Research* 1997;41:264-67.
- 143 Willis DS, Wishart JG, Muir WJ. Menopausal experiences of women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 2011;24:74-85.
- 144 DCSF (2008) The Berrow Report A Review of Services for Children and Young People (0-19) with Speech, Language and Communication Needs
- 145 DfE (2012) Understanding speech, language and communication needs: Profiles of need and provision (2012)
- 146 Enderby, P. et al (2009) Resource Manual for Commissioning and Planning Services for SLCN. Royal College of Speech and Language Therapists
- 147 The Clinical and Health Outcomes Knowledge Base (2005) information on health outcomes generated by NCHOD
- 148 The Clinical and Health Outcomes Knowledge Base (2005) information on health outcomes generated by NCHOD
- 149 HSCIC Compendium of population health indicators (2015) Incidence of Downs Syndrome
- 150 Alzheimers Society (2015) Learning Disabilities and Dementia
- 151 Alzheimers Society (2015) Learning Disabilities and Dementia
- 152 Wright, B., Williams, C., and Richardson, G. (2008) Services for children with learning disabilities, in *Psychiatric Bulletin* (2008)
- 153 Emerson E, Hatton C (2007) Mental health of children and adolescents with intellectual disabilities in Britain. *British Journal of Psychiatry*, 191, 493-499.
- 154 Wright, B., Williams, C., and Richardson, G. (2008) Services for children with learning disabilities, in *Psychiatric Bulletin* (2008)
- 155 Emerson E and Hatton C. 2007. The Mental Health of Children and Adolescents with Learning Disabilities in Britain. Lancaster University
- 156 Department for Children, Schools and Families (October 2009) Children with special educational needs 2009: an analysis
- 157 Emerson E and Hatton C. 2007. The Mental Health of Children and Adolescents with Learning Disabilities in Britain. Lancaster University
- 158 Rosenblatt, M (2008). *I Exist: the message from adults with autism in England*. London: The National Autistic Society
- 159 ESCC ASC Performance and Engagement Unit (2016)
- 160 British and Irish Network of Congenital Anomaly Researchers (BINOCAR) (2014) The National Down Syndrome Cytogenetic Register for England and Wales: 2013 Annual Report. Queen Mary University of London, Barts and The London School of Medicine and Dentistry
- 161 Budd et al (2015) Socioeconomic inequalities in pregnancy outcome associated with Down syndrome: a population-based study. Published in *Arch Dis Child Fetal Neonatal Ed* doi:10.1136
- 162 Public Health England (2016) Health and Care for people with learning disabilities. Gyles Glover conference presentation
- 163 Public Health England (2016) Health and Care for people with learning disabilities. Gyles Glover conference presentation
- 164 Public Health England (2016) Health and Care for people with learning disabilities. Gyles Glover conference presentation
- 165 Fraser S, Sim J. The Sexual Health Needs of Young People with Learning Disabilities. Edinburgh: Health Scotland, 2007.
- 166 Public Health England (2015) Learning Disability Profiles: Indicator Definitions and supporting information <http://fingertips.phe.org.uk/profile/learning-disabilities/data#page/6/gid/1938132703/pat/6/par/E12000008/ati/102/are/E10000011/iid/91438/age/168/sex/4>
- 167 <http://www.nhs.uk/Livewell/Childrenwithalearningdisability/Pages/AnnualHealthChecks.aspx>
- 168 Public Health England (2015) Learning Disability Profiles <http://fingertips.phe.org.uk/profile/learning-disabilities>
- 169 ONS (2016) MYE2: Population Estimates by single year of age and sex for local authorities in the UK, mid-2015
- 170 Mencap (2011) Inclusive support for parents with a learning disability. A project funded by the Department of Health
- 171 Nocon A and Sayce L (2008). Primary healthcare for people with mental health problems or learning disabilities. *Health Policy*
- 172 Public Health England (2016) Health and Care for people with learning disabilities. Gyles Glover
- 173 <http://www.improvinghealthandlives.org.uk/projects/primarycaredata/details>
- 174 ESCC ASC Strategy, Commissioning and Supply Management (March 2016) Control provider management database
- 175 ESCC ASC Strategy, Commissioning and Supply Management (March 2016) Control provider management database
- 176 ESCC ASC Strategy, Commissioning and Supply Management (March 2016) Control provider management database

- 177 Emerson E, Turnbull L. Self-reported smoking and alcohol use by adolescents with and without intellectual disabilities. *Journal of Intellectual Disabilities* 2005;9(1):58-69.
- 178 Department for Children, Schools and Families (October 2009) Children with special educational needs 2009: an analysis.
- 179 Emerson and Baines (2010) Health Inequalities and people with learning disabilities in the UK: 2010. IHaL and Department of Health
- 180 Emerson and Baines (2010) Health Inequalities and people with learning disabilities in the UK: 2010. IHaL and Department of Health
- 181 Robertson J, Emerson E, Gregory N, Hatton C, Turner S, Kessissoglou S, et al. Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities. *Research in Developmental Disabilities* 2000;21(6):469-86.
- 182 Chimat (2011) Disability and obesity: the prevalence of obesity in disabled children Chimat (2011) Disability and obesity: the prevalence of obesity in disabled children
- 183 Emerson and Baines (2010) Health Inequalities and people with learning disabilities in the UK: 2010. IHaL and Department of Health
- 184 HSCIC (2015) Personal Social Services Survey of Adult Carers in England, 2014-15
- 185 Bennett, E. (2009) What makes my family stronger: A report into what makes families with disabled children stronger – socially, emotionally and practically. Contact a Family May 2009
- 186 <http://www.learningdisabilities.org.uk/help-information/Learning-Disability-Statistics-/187696/> cited by Local Government Knowledge Navigator (2014) What Councils Need to Know about People with Learning Disabilities. Dr Paula Black
- 187 <http://www.learningdisabilities.org.uk/help-information/Learning-Disability-Statistics-/187696/> cited by Local Government Knowledge Navigator (2014) What Councils Need to Know about People with Learning Disabilities. Dr Paula Black
- 188 ESCC Planning performance and engagement (2016)
- 189 <http://www.learningdisabilities.org.uk/help-information/Learning-Disability-Statistics-/187696/> cited by Local Government Knowledge Navigator (2014) What Councils Need to Know about People with Learning Disabilities. Dr Paula Black
- 190 <http://www.improvinghealthandlives.org.uk/gsf.php5?f=16453&fv=17942>
- 191 Royal College of Nursing (2016) Connect for change: an update on learning disability services in England
- 192 Health and Social Care Information Centre, *Learning Disability Census 2015* www.hscic.gov.uk/catalogue/PUB19428/ld-census-initial-sep15-rep.pdf (p. 76)
- 193 National Audit Office (2015) Care services for people with learning disabilities and challenging behaviour
- 194 National Audit Office (2015) Care services for people with learning disabilities and challenging behaviour
- 195 NHS England (2016) Learning Disability bed stock, the regional picture so far
- 196 Draft Transforming Care Plan (data accessed March 2016)
- 197 NHS Choices (Accessed September 2016) Your guide to care and support: mental health aftercare
- 198 IHaL (2013) Hospital admissions that should not happen. Glover and Evison. Supported by Department of Health [https://www.improvinghealthandlives.org.uk/publications/1169/Hospital admissions that should not happen](https://www.improvinghealthandlives.org.uk/publications/1169/Hospital%20admissions%20that%20should%20not%20happen)
- 199 IHaL (2013) Hospital admissions that should not happen. Glover and Evison. Supported by Department of Health [https://www.improvinghealthandlives.org.uk/publications/1169/Hospital admissions that should not happen](https://www.improvinghealthandlives.org.uk/publications/1169/Hospital%20admissions%20that%20should%20not%20happen)
- 200 Glover G, Ayub M. How people with learning disabilities die. (2010) Improving Health and Lives: Learning Disabilities Observatory, <http://www.improvinghealthandlives.org.uk/gsf.php5?f=8586&fv=9033>
- 201 IHaL (2013) Hospital admissions that should not happen. Glover and Evison. Supported by Department of Health [https://www.improvinghealthandlives.org.uk/publications/1169/Hospital admissions that should not happen](https://www.improvinghealthandlives.org.uk/publications/1169/Hospital%20admissions%20that%20should%20not%20happen)
- 202 IHaL (2013) Hospital admissions that should not happen. Glover and Evison. Supported by Department of Health [https://www.improvinghealthandlives.org.uk/publications/1169/Hospital admissions that should not happen](https://www.improvinghealthandlives.org.uk/publications/1169/Hospital%20admissions%20that%20should%20not%20happen)
- 203 ONS and ESCC Projections run in October 2015
- 204 http://www.improvinghealthandlives.org.uk/uploads/doc/vid_10673_IHaL2011-05FutureNeed.pdf
- 205 http://www.improvinghealthandlives.org.uk/uploads/doc/vid_10673_IHaL2011-05FutureNeed.pdf
- 206 Local Government Knowledge Navigator (2014) What Councils Need to Know about People with Learning Disabilities. Dr Paula Black
- 207 Adult Social Care Efficiency Programme: Interim Report 2013, Local Government Association, p.11.
- 208 Local Government Knowledge Navigator (2014) What Councils Need to Know about People with Learning Disabilities. Dr Paula Black
- 209 Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England (2008) http://eprints.lancs.ac.uk/21049/1/CeDR_2008-6_Estimating_Future_Needs_for_Adult_Social_Care_Services_for_People_with_Learning_Disabilities_in_England.pdf
- 210 Local Government Knowledge Navigator (2014) What Councils Need to Know about People with Learning Disabilities. Dr Paula Black
- 211 Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England (2008) http://eprints.lancs.ac.uk/21049/1/CeDR_2008-6_Estimating_Future_Needs_for_Adult_Social_Care_Services_for_People_with_Learning_Disabilities_in_England.pdf
- 212 http://eprints.lancs.ac.uk/21049/1/CeDR_2008-6_Estimating_Future_Needs_for_Adult_Social_Care_Services_for_People_with_Learning_Disabilities_in_England.pdf
- 213 The Clinical and Health Outcomes Knowledge Base (2005) information on health outcomes generated by NCHOD
- 214 PANSI (accessed March 2016) Downs Syndrome: East Sussex
- 215 Alzheimers Society (2015) Learning Disabilities and Dementia
- 216 Lowe et al (2007) Challenging behaviours: Prevalence and Topographies, published in the *Journal of Intellectual Disability Research*, Volume 51, August 2007.
- 217 Local Government Knowledge Navigator (2014) What Councils Need to Know about People with Learning Disabilities. Dr Paula Black
- 218 Emerson and Baines (2010) Health Inequalities and people with learning disabilities in the UK: 2010. IHaL and Department of Health
- 219 Local Government Knowledge Navigator (2014) What Councils Need to Know about People with Learning Disabilities. Dr Paula Black
- 220 Adult Social Care Efficiency programme 1: The initial position (2012), The Local Government Association
- 221 Winterbourne View Review: Good Practice Examples, Department of Health, no date.
- 222 Rewiring public services – adult social care and health, LGA, 28/6/2013.
- 223 Guidance for commissioners of mental health services for people with learning disabilities (May 2013) Joint Commissioning Panel for Mental Health <http://www.jcpmh.info/wp-content/uploads/jcpmh-learningdisabilities-guide.pdf>
- 224 Cooper, O. and Warren, S. (2010) All together NOW: Collectively figuring how to develop alternatives to just paid support, Northwest Joint Improvement Partnership. <http://www.thinklocalactpersonal.org.uk/Browse/commissioning/developing/?parent=8567&child=8432>
- 225 Emerson, E. Hatton, C. and Robertson, J. (2011) Prevention and Social Care for Adults with Learning Disabilities http://eprints.lse.ac.uk/41200/1/SSCR_scoping_review_Emerson.pdf