

## **West Sussex County Council**

### **Comprehensive needs assessment of the life pathway for people with disabilities**

### **Epidemiological Report**

**May 2016**

# West Sussex County Council

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### Epidemiological Report

#### Headline findings

The total population aged 0-24 years in West Sussex is projected to increase by just under 7% in the next 20 years from 225,900 to 241,700.

Using Family Resources Survey (FRS) age-related prevalence rates, there are an estimated 15,100 children and young people with a disability aged 0-24 years in West Sussex in 2015, projected to increase to 16,400 in 2035, an increase of 8.6%.

Using FRS age-related prevalence rates, there are an estimated 3,500 children and young people with a disability aged 10-14 years, and 3,200 aged 15-19 years in West Sussex.

In West Sussex, there are an estimated 131 children and young people with a severe disability aged 0-19. With some potential overlap there are an estimated 118 people predicted to have a severe learning disability aged 18-24; and 456 people predicted to have a serious physical disability aged 18-24.

There are 113 children and young people who are severely sight impaired or blind aged 0-16 years and 37 people aged 18-24 predicted to have a severe visual impairment in West Sussex based on ChiMat<sup>1</sup> and PANSI data.

There are 54 children and young people aged 0-17 years who are registered deaf and 83 people aged 18-24 predicted to have a moderate or severe hearing impairment in West Sussex based on ChiMat<sup>2</sup> and PANSI data.

There are an estimated 120 people with Down's Syndrome aged 0-24 years old in the county.

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<sup>1</sup> Child and Maternal Health Observatory.

<sup>2</sup> Child and Maternal Health Observatory.

There are an estimated 2,622 children and young people aged 0-24 years with autism in West Sussex in 2015, rising to 2,796 by 2030.

It is estimated that there are 80 children and young people with a learning disability predicted to display challenging behaviour in West Sussex in 2015

In January 2015, there were 20,656 school pupils with statements or EHC plans or SEN support in West Sussex.

In terms of school pupils with special educational needs in West Sussex in January 2015, by primary type of need, there were:

- 3,781 with speech, language and communication needs
- 3,210 with a moderate learning difficulty
- 3,091 with a specific learning difficulty
- 120 with a profound and multiple learning difficulty
- 509 with a physical disability.

The research evidence on the outcomes of children and young people with disabilities clearly indicates that along the life pathway they experience poorer outcomes than the general population. In terms of their health, housing, economic, employment and social outcomes, children and young people with disabilities have poorer outcomes than their peers.

There is an ongoing need for commissioners to find ways to improve these outcomes for the growing numbers of children and young people with disabilities in West Sussex.

## 1 Introduction

Children, young people and adults with a lifelong disability are a diverse group. Some will have highly complex needs requiring multi-agency support across health, social services and education. Others will require substantially less support, although nevertheless have a long-term disability.

At the national level, there have been numerous attempts to provide accurate estimates of disability in children and young people. Some of these have provided condition-based estimates based on the literature, and others have utilised specific survey data. Information on self-reported (by the parent) long-standing illness or disability is available from the Census and the Family Resources Survey (formerly the General Household Survey). The Census uses the following definition of disability:

*“A long-term health problem or disability that limits a person's day-to-day activities, and has lasted, or is expected to last, at least 12 months.”*

Extensive information on disability is collected in the Family Resources Survey (FRS) - one of the key sources of information on the population of disabled children and adults. The estimates for disabled people cover the number of people with: ‘*a long-standing illness, disability or impairment which causes substantial difficulty with day-to-day activities*’.

Everyone classified as disabled under this definition would also be classified as disabled under the general definition of disability in the Equality Act (EA) which has applied since 1 October 2010. However, some individuals classified as disabled and having rights under the EA would not be captured by the FRS definition.

Routine data are collected by local authorities on children with statements of Special Educational Needs/ EHC Plans, but this does not reflect the spectrum of disability, and is a weak proxy measure for severity. However, the data do indicate demand and how it is changing over time. West Sussex County Council does not currently have a Disability Register.

Thus, different sources of data provide different information on the needs of children, young people, and also adults with a disability. In some cases they are not directly comparable, as some indicate prevalence, while others reflect expressed demand for services. As long as these differences are taken into account when making conclusions, each data source provides an insight into numbers of people with lifelong disabilities that this needs assessment aims to study.

This report focuses on children and young adults with disabilities from 0-24 years old, covering: current and future populations; special educational needs; and outcomes for children and young people with disabilities.

## 2 Current and future populations

### 2.1 Total projected population of children and young people

Table 1 indicates the current total number of children and young people in West Sussex and how the numbers are expected to change over the next 20 years. The greatest numbers are in Mid-Sussex, Arun and Horsham districts; and the lowest number is in Adur district. The total population aged 0-24 years is projected to increase by just under 7% in the next 20 years<sup>3</sup>.

Over the last 10 years the number of children aged 5-15 years has decreased, but there has been a 17% increase of 0-4 year olds over that same period (2,500 children) which will contribute to a growth in numbers reaching the age of transition from 2015 on.

**Table 1: Projected population in West Sussex aged 0-24, including figures for districts, 2015-2035**

Council area	2015	2020	2025	2030	2035
Adur	16,600	17,000	17,300	17,700	17,700
Arun	38,300	39,000	40,100	41,400	41,800
Chichester	30,700	31,300	32,100	33,200	33,500
Crawley	34,900	36,400	37,800	38,800	39,000
Horsham	36,300	36,000	36,500	37,000	37,000
Mid Sussex	40,200	40,800	41,600	42,200	42,200
Worthing	28,900	29,300	29,800	30,400	30,500
<b>West Sussex</b>	<b>225,900</b>	<b>229,900</b>	<b>235,200</b>	<b>240,800</b>	<b>241,700</b>

*Figures from ONS population projections based on sub-national population estimates, 2012. Subject to rounding.*

### 2.2 Prevalence of disability in children

National data suggest that the health of young people in West Sussex is generally better than the England average, reflecting the lower levels of deprivation and generally better living conditions among West Sussex families<sup>4</sup>. Young people in West Sussex tended to be in good health, with 97.7% of those aged 0-15 years indicating good or very good health across all districts – above the rate for the South East and the rest of England<sup>5</sup>.

<sup>3</sup> Based on ONS and WSCC population projections

<sup>4</sup> WSCC (2015) Annual Public Health Report 2014/15

<sup>5</sup> WSCC (2015) West Sussex Life, 2014 Available at:

<https://www.westsussex.gov.uk/about-the-council/information-and-data/reports/west-sussex-life/>

There are a number of possible ways to estimate the number of children and young people with disabilities in West Sussex.

### 2.2.1 Estimates based on the Family Resources Survey

Using disability prevalence rates by age in the Family Resources Survey (FRS)<sup>6</sup>, applied to population projections for children and young people, there are **just over 15,000 children and young people with a disability aged 0-24 years** in West Sussex in 2015. This figure is projected to be nearly 9% over the next 20 years to more than 16,300 (Table 2).

**Table 2: Children and young people aged 0-24 in West Sussex projected to have a disability, 2015-2035**

Council area	2015	2020	2025	2030	2035
Adur	1,000	1,100	1,100	1,100	1,100
Arun	2,600	2,600	2,700	2,800	2,900
Chichester	2,100	2,100	2,200	2,300	2,300
Crawley	2,300	2,400	2,500	2,600	2,600
Horsham	2,400	2,400	2,500	2,500	2,500
Mid Sussex	2,700	2,700	2,800	2,800	2,900
Worthing	1,900	2,000	2,000	2,100	2,100
<b>West Sussex total</b>	<b>15,100</b>	<b>15,400</b>	<b>15,800</b>	<b>16,300</b>	<b>16,400</b>

*Figures calculated using prevalence rates of 3% for age 0-4, 7% for 5-10, 8% for 11-14, 7% for 15-19 and 9% for 20-24 from FRS 2011/12. Subject to rounding.*

Mid Sussex, Arun and Horsham districts have the highest numbers of children and young people with disabilities, while Adur district has the lowest number.

Table 3 provides a breakdown of projected numbers by age between 2015 and 2035. A full breakdown by age and district is provided in Appendix I.

Of relevance to planning the transition to adulthood, the data indicate that in 2015, there were: over 3,540 young people aged 10-14; over 3,170 young people aged 15 to 19; and over 3,580 young people aged 20-24 across the county with a disability. The number of young people aged 10-19 with a disability is projected to increase significantly between 2015 and 2035 in West Sussex which will have implications for the pathway to adulthood.

<sup>6</sup> DWP/ONS (2013) Family Resources Survey, United Kingdom, 2011/12.

**Table 3: Children and young people aged 0-24 in West Sussex projected to have a disability by age quintiles, 2015-2035**

Age quintile	2015	2020	2025	2030	2035	2015-35 % change
0-4	1,400	1,400	1,400	1,400	1,400	-2.5%
5-9	3,300	3,500	3,400	3,400	3,400	1.2%
10-14	3,500	4,000	4,200	4,200	4,100	16.8%
15-19	3,200	3,000	3,500	3,600	3,600	12.6%
20-24	3,600	3,400	3,300	3,700	3,900	8.3%
<b>Total</b>	<b>15,100</b>	<b>15,400</b>	<b>15,800</b>	<b>16,300</b>	<b>16,400</b>	<b>8.6%</b>

*Figures calculated using prevalence rates of 3% for age 0-4, 7% for 5-10, 8% for 11-14, 7% for 15-19 and 9% for 20-24 from FRS 2011/12. Subject to rounding.*

### 2.2.2 Estimates based on the national Child and Maternal Health Observatory (ChiMat)

The national Child and Maternal Health Observatory (ChiMat) estimates that there are **between 4,628 and 8,330 children under 18 years** in West Sussex experiencing some form of disability. ChiMat uses research by the Thomas Coram Research Unit (TCRU) which indicates the mean percentage of disabled children in English local authorities is between 3.0 percent and 5.4 percent under 18 years. The calculation was based on the number of children with a statement of Special Educational Needs *and* in receipt of Disability Living Allowance (DLA)<sup>7</sup>.

However, based on other data, ChiMat estimate a much higher figure of **over 32,600 children aged 0-19 years** with a long-standing illness or disability in West Sussex, of whom **131 have a severe disability** (which is not explained by the slightly different age group included in the estimate). Using ONS based data on the health of children and young people, Table 4 below presents ChiMat's estimated numbers for mild and severe disability in children aged 0-19 years old. The number with mild disabilities rises and then falls with age, while those with a severe disability declines steadily with age. There are estimated to be more than double the number of boys than girls with a severe disability.

<sup>7</sup> Mooney A et al (2008) Disabled Children: Numbers, Characteristics and Local Service Provision. Report to DCSF, Thomas Coram Research Unit & Institute of Education, University of London.

**Table 4: Age-specific estimates (population aged 0 to 19 years) with long-standing illness or disability in West Sussex**

Living with longstanding illness or disability	Mild disability	Severe disability
Boys age 0-4	3,374	36
Boys age 5-9	5,625	27
Boys age 10-14	4,740	19
Boys age 15-19	4,320	7
Total boys age 0-19	18,059	89
Girls age 0-4	2,925	18
Girls age 5-9	3,762	10
Girls age 10-14	4,161	9
Girls age 15-19	3,584	4
Total girls age 0-19	14,432	42
<b>Total boys and girls aged 0-19</b>	<b>32,491</b>	<b>131</b>

Source: ONS/Family Fund Trust/ChiMat

According to the latest WSCC Annual Public Health Report (2014/15) there are 7,000 (3.8%) children and young people aged 0-19 with a long term health condition or disability which limits their daily living activities. This is comprised of 1.8% of 0-4 year olds, rising to 5.2% of 15-19 year olds<sup>8</sup>.

**For those aged 18-24, according to PANSI<sup>9</sup>, there are an estimated 118 people predicted to have a severe learning disability out of 357 with a moderate or severe learning disability; and 456 people predicted to have a serious physical disability compared with 2,337 with a moderate physical disability in West Sussex.**

### 2.2.3 Comment

These varying estimates indicate the range of approaches that are available. Given the definition of disability used in the FRS, it is considered to be the most relevant basis for the assessment of need in West Sussex, while the ChiMat figures highlight differences in prevalence by gender, and a sharp difference between the numbers with mild and more severe disabilities (which is also indicated in the PANSI data).

Continuing developments in medical technology mean that the number of children living through birth and early years is increasing. This not only

<sup>8</sup> WSCC (2015) Annual Public Health Report 2014/15

<sup>9</sup> <http://www.pansi.org.uk/>



means there is a greater number of children and young people who are in need of a social care intervention, but also that the complexity of the care need is greater. This will put greater pressure on services for more intensive support. Numbers are also increasing as a result of better diagnosis of conditions such as autism.

### 2.3 Estimates of mobility impairment

There is limited evidence on the prevalence of mobility impairments in children and young people. However, the Life Opportunities Survey indicates that 1% of people aged 16 to 34 has a mobility impairment<sup>10</sup>. Using the FRS-based estimate of the number of children and young people in Wes Sussex and applying the 1% rate to the total would indicate that there are 151 children and young people aged 0-24 years with a mobility impairment in the county.

### 2.4 Estimates of prevalence of visual impairment

The Royal National Institute for the Blind (RNIB) provides data on the prevalence of visual impairment in children and young people<sup>11</sup> which reports that two in every 1,000 (0.2%) children and young people up to the age of 25 in the UK have vision impairment. Variation in definitions and service provision means that caution is required in interpreting any single estimate of the prevalence of visual impairment or blindness among children and young people in the UK.

Table 5 indicates what the prevalence rates of different forms of visual impairment mean in terms of current and future numbers of children and young people with varying types of visual impairment. Rates have been applied to the total population aged 0-24 years.

Over 450 children and young people are estimated to have some level of visual impairment in West Sussex: 113 children aged 0-16 years are estimated to be severely sight impaired or blind, and 37 young people aged 18-24 are predicted to have a severe visual impairment<sup>12</sup>. This compares with 129 school pupils in West Sussex in January 2015 with a visual impairment (across primary, secondary and special schools by primary type of need).

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<sup>10</sup> Defined as 'they experience either moderate, severe or complete difficulty within at least one area of physical functioning, and certain activities are limited in any way as a result. 'Activities' refer to different areas of physical functioning, such as walking, or climbing stairs'. Office for Disability Issues (2011) *Life Opportunities Survey Wave One Results 2009-11*, Crown Copyright.

<sup>11</sup> Available at: <http://www.rnib.org.uk/cy/knowledge-and-research-hub/key-information-and-statistics>

<sup>12</sup> <http://www.pansi.org.uk/>

**Table 5: Visual Impairment estimates for children and young people aged 0-24 years in West Sussex**

Age group	Visual impairment	2015	2035
0-24	Visual impairment (0.2% prevalence)	451	483
0-16	Severely sight impaired or blind (0.05% prevalence)	113	120
0-19	Co-occurring vision and hearing impairments (0.031% prevalence)	70	75
0-17	Registered blind (0.028% of total population)	63	68
0-17	Partially sighted (0.031% of total population)	70	75

Source: ChiMat

Around half the children receiving support from visual impairment services may have additional disabilities, and this proportion may be even higher for children with severe visual loss. In a study by Rahi and Cable<sup>13</sup>, 77% of children newly diagnosed with severe visual impairment or blindness had additional non-ophthalmic disorders or impairments. Keil found that around 20 per cent of young people with visual impairment have additional special educational needs and/or disabilities (SEND) and a further 30 per cent have complex needs<sup>14</sup>. A re-analysis of the 1989 Office of Population Censuses and Surveys (OPCS) child disability survey showed that children were likely to either have a mild to moderate visual impairment with few other disabilities, or to have visual impairments of a more severe nature, along with several other disabilities also of a severe or profound nature.

Rahi and Cable observe that the characteristics of the population of children with severe sight problems or blindness are changing. This is because:

- There has been a decline in the incidence of treatable or preventable disorders such as retinopathy of prematurity and congenital cataract, which is linked to improvements in primary prevention, early detection and medical and surgical management.
- There has been an increase in untreatable disorders such as cerebral sight problems, the inherited retinal dystrophies, optic nerve atrophy and hypoplasia. The increase is linked with changing trends in childhood chronic disease and disability that are themselves linked with increased survival of premature and very low birth weight babies and children with major anomalies, complex neurological and metabolic diseases and malignant disease.

<sup>13</sup> Rahi J and Cable N (2003) 'Severe visual impairment and blindness in children in the UK' *The Lancet*, Vol 362, Oct 25, 2003.

<sup>14</sup> Keil (2014) Local authority Vision Impairment (VI) education service provision for blind and partially sighted children and young people: Report on findings from RNIB Freedom of Information (FOI) requests 2013, RNIB.

The consequences of these changes are that:

- Proportionally more children with severe sight problems and blindness now have additional - often very complex - disabilities. 77% of children in the study had additional non-ophthalmic disorders or impairments.
- Very premature and low birth weight babies are at particular risk of severe sight problems and blindness.
- There is an increased rate of severe sight problems and blindness in children from ethnic minorities. There is also an association with socio-economic deprivation. These two factors may also be correlated, although with certain ethnic groups where inter-cousin marriages are common, autosomal recessive disorders are found.

## **2.5 Deaf and hard of hearing**

In 2010 there were 0.9 per 10,000 population aged 0-17 in West Sussex who were registered as hard of hearing and 2.4 per 10,000 population aged 0-17 who were registered deaf.

Assuming that the rate has not changed, this would indicate 20 children aged 0-17 who are registered as hard of hearing (and this will rise to 22 in 2035) and 54 who are registered deaf in 2015. There were 83 young people aged 18-24 predicted to have a moderate or severe hearing impairment according to PANSI. This compares with 237 school pupils in West Sussex in January 2015 with a hearing impairment (across primary, secondary and special schools by primary type of need). This indicates that not all children and young people with a hearing impairment are registered as deaf or hard of hearing.

## **2.6 Learning disability**

Table 6 below presents the estimated number of children and young people up to the age of 24 predicted to have a learning difficulty (sic) in West Sussex. The figures are based on Emerson and Hatton's Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England (2008). Estimates for higher age groups are available in Appendix II.

**Table 6: Children and young people aged 0-24 predicted to have a learning difficulty in West Sussex**

Age group	2015			2020			2025			2030		
	Moderate LD	Severe LD	Profound and multiple LD	Moderate LD	Severe LD	Profound and multiple LD	Moderate LD	Severe LD	Profound and multiple LD	Moderate LD	Severe LD	Profound and multiple LD
0-4	1,705	220	54	1,690	219	54	1,674	217	53	1,658	214	53
5-9	1,745	226	56	1,809	234	58	1,798	232	57	1,783	231	57
10-14	1,587	205	51	1,808	234	58	1,875	243	60	1,867	241	59
15-19	1,624	210	52	1,556	201	50	1,770	229	56	1,834	237	58
20- 24	1,425	184	45	1,364	176	43	1,304	169	42	1,479	191	47
<b>Total</b>	<b>8,086</b>	<b>1,046</b>	<b>257</b>	<b>8,229</b>	<b>1,064</b>	<b>262</b>	<b>8,422</b>	<b>1,089</b>	<b>268</b>	<b>8,620</b>	<b>1,115</b>	<b>275</b>

Note: Rates for children and young people with a learning difficulty are as follows: Moderate learning difficulty 3.580%; Severe learning difficulty 0.463%; Profound and multiple learning difficulty 0.114%.

Moderate Learning Difficulties includes children who have difficulties in all areas of learning. Their rate of progress is very slow. They attend mainstream schools unless they also have additional significant difficulties when they may be placed into a special school.

Severe Learning Difficulties describes children who show a global delay in all areas of physical, intellectual and social development. Their rate of progress is less than half the rate of other children of the same age. These children will have a statement of special educational need.

Profound and Multiple Learning Difficulties have severe and complex learning needs, in addition they have other significant difficulties, such as physical disabilities or a sensory impairment. Pupils require a high level of adult support, both for their learning needs and also for personal care.

## 2.7 Down's syndrome

Table 7 provides an estimate of the number of children and young people with Down's syndrome in West Sussex based on the application of prevalence rates to population projections. There are an **estimated 120 people with Down's Syndrome aged 0-24 years old** in the county.

**Table 7: People aged 0-24 predicted to have Down's syndrome, by age, projected to 2030 in West Sussex**

People predicted to have Down's syndrome	2015	2020	2025	2030
0-4	25	25	25	25
5-9	26	27	27	27
10-14	24	27	28	28
15-19	24	23	26	27
20-24	21	20	19	22
<b>Total</b>	<b>120</b>	<b>122</b>	<b>125</b>	<b>129</b>

Figures may not sum due to rounding. Crown copyright 2014<sup>15</sup>

## 2.8 Prevalence of Autism Spectrum Disorder (ASD)

According to the National Autistic Society, the latest prevalence studies of autism indicate that 1.1% of the population in the UK may have autism. This would indicate that there are **2,622 children and young people aged 0-24 years with autism** in West Sussex in 2015, rising to 2,796 by 2030.

**Table 8: People aged 0-24 predicted to have autistic spectrum disorders, by age and gender, projected to 2030 in West Sussex**

People predicted to have autistic spectrum disorders	2015	2020	2025	2030
0-4	553	548	543	538
5-9	566	587	583	578
10-14	515	586	608	605
15-19	527	505	574	595
20-24	462	442	423	480
<b>Total</b>	<b>2,622</b>	<b>2,669</b>	<b>2,731</b>	<b>2,796</b>

Figures may not sum due to rounding. Crown copyright 2014<sup>16</sup>

<sup>15</sup> The prevalence rate for this table is based on two studies which put the prevalence of Down's syndrome at between 5.9 per 10,000 general population (Mantry et al) and 6.6 per 10,000 live births (the Clinical and Health Outcomes Knowledge Base). The mean of these rates, 6.25 per 10,000 population, has been used.

This compares with 759 (Table 9) or 1,025 (Table 12) school pupils in West Sussex in January 2015 with ASD (across primary, secondary and special schools by primary type of need ); indicating that not all children and young people with ASD have a statement or EHC plan, and some children may be misdiagnosed. The contrasting figures from Tables 9 and 12 also highlight some of the difficulties in obtaining reliable and accurate data on disability.

**Table 9: Number of children in West Sussex schools with ASD by primary need**

Year	Number of children with ASD by primary need
2011	610
2012	635
2013	676
2014	723
2015	759

*Source: SEND Data from BSL*

Five times as many males as females are diagnosed with autism and between 44% and 52% of people with autism may have a learning disability.

The number of children with ASD appears to be steadily increasing – which may reflect better diagnosis due to increased public and medical awareness.

## 2.9 Challenging behaviour

The prevalence rate for people with a learning disability displaying challenging behaviour is 0.045% of the population aged 5 and over<sup>17</sup>. In total, 4.5 people per 10,000 of the population aged 5 and over were rated as seriously challenging (representing approximately 10% of the learning disability population). The most prevalent general form of challenging behaviour was 'other difficult/disruptive behaviour', with non-compliance being the most prevalent challenging behaviour.

Applying this rate to the ONS population projections gives **an estimated 80 children and young people with a learning disability predicted to display challenging behaviour** in West Sussex in 2015, rising to 88 by 2030 (Table 10).

<sup>16</sup> The information about ASD is based on Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007 was published by the Health and Social Care Information Centre in September 2009.

<sup>17</sup> Lowe et al (2007) Challenging behaviours: Prevalence and Topographies, Journal of Intellectual Disability Research, Volume 51, August 2007.

**Table 10: Children, young people and adults aged 5-64 with a learning disability, predicted to display challenging behaviour, by age, projected to 2030**

Age group	2015	2020	2025	2030
5-9	22	23	23	22
10-14	20	23	24	23
15-19	20	20	22	23
20-24	18	17	16	19
<b>Total</b>	<b>80</b>	<b>82</b>	<b>85</b>	<b>88</b>

*Note: Figures may not sum due to rounding. Crown copyright 2014*

## 2.10 Communication disorders

Around 7% of children in the UK have specific and primary speech and language impairments<sup>18</sup>. Applying this prevalence rate to the local population would indicate there were over 15,800 children and young people aged 0-24 years in West Sussex with some level of speech and language impairment. However, this includes children who have speech, language or communication needs as a result of another condition such as autism, hearing impairment, general learning Difficulties, so there will be a degree of overlap with other groups identified in this needs assessment, and some who would not necessarily consider that they have a disability.

## 2.11 Ethnic minorities and disability

Some ethnic minorities demonstrate a higher prevalence of disabilities. The causes for higher disability prevalence rate within certain communities are complex with both environmental and genetic reasons having an effect. Nationally, some support services on offer have been shown to be culturally inappropriate for some groups. The proportion of the population from black and minority ethnic groups in West Sussex is relatively low, below 7% in the adult population, compared with the national figure of 15%. However, proportion rises to 20% in Crawley district.

## 2.12 Prevalence rates of learning disability by socio-economic background

Children from poorer families are more likely to have a learning disability. According to ChiMat, the prevalence rates of children and adolescents with mild disabilities have been found to be higher for those from semi-skilled manual and unskilled manual family backgrounds. The rate of severe disability was found to be greatest amongst children from semi-skilled manual family backgrounds,

<sup>18</sup> Tomblin, J.B. et al (1997) 'Prevalence of Specific Language Impairment in Kindergarten Children', *Journal of Speech, Language and Hearing Research*, 40 in Lindsay, G. and Dockrell, J. with Mackie, C. and Letchford, B. (2002) Educational Provision for Children with Specific Speech and Language Difficulties in England and Wales CEDAR 4.

whilst the lowest rates were for children from professional and managerial family background.

In 2012, 12.4% of all children were living in relative poverty in West Sussex, but this varied across the county. Crawley had the highest rate of child poverty in the county (17.4%), Mid-Sussex the lowest (7.7%) and Ham ward in Arun remained the ward with the highest child poverty rate of 33.3%<sup>19</sup>.

### 2.13 Low birthweight

Infants born at a low birthweight are also at increased risk of long-term disability and impaired development<sup>20</sup>. Infants born weighing less than 2,500 grams are more likely than heavier infants to experience delayed motor and social development<sup>21</sup>. Lower birthweight also increases a child's likelihood of having a school-age learning disability, being enrolled in special education classes, having a lower IQ, and dropping out of high school<sup>22</sup>. Risk for many of these outcomes increases substantially as birthweight decreases, with very low birthweight babies being most at risk of disability.

The rate of low birthweight babies in West Sussex is below the national average. In 2014, there were 558 low birth weight live births in West Sussex (Table 11).

**Table 11: Low birthweight numbers and rates in West Sussex and South East region, 2014**

	Percentage of live births under 2.5kg	Number of low birthweight live births
West Sussex	6.4	558
South East region	6.2	6,349
England	7.0	46,305

Source: Public Health England

## 3 Special Educational Needs

Data on children with Special Educational Needs (SEN) as reported by schools gives an indication of numbers in the county. Pupils with SEN have disabilities or learning difficulties that make it harder for them to learn than most pupils of the same age. Rates will vary depending on the policies and practices of local

<sup>19</sup> WSCC (2015) Annual Public Health Report 2014/15.

<sup>20</sup> Reichman, N (2005) Low birth weight and school readiness. In School readiness: Closing racial and ethnic gaps. *The Future of Children*, 15(1), 91-116.

<sup>21</sup> Hediger, M. L., Overpeck, M. D., Ruan, W. J., and Troendle, J. F. (2002) Birthweight and gestational age effects on motor and social development. *Pediatric and Prenatal Epidemiology*, 16, pp33-46.

<sup>22</sup> Jackson, M. I. (2006) Why do low birth weight children do worse in school? Understanding the link between infant health and education. Conference Papers: American Sociological Association, Annual Meeting, Montreal. pp. 1-25.



authorities (SEN classification is not totally consistent across local authorities). In addition, some children with disabilities will not appear in the SEN data. It is estimated that approximately one in every five pupils nationally has a special educational need.

Table 12 presents the number of pupils with SEN in primary, secondary and special schools across West Sussex by primary type of need in January 2015. More detailed tables are available in Appendix II.

In January 2015, there were a total of **16,486 school pupils** with special educational needs (SEN), of whom more than 6,800 were identified as having some level of learning difficulty as their primary type of need, and 1,025 as having ASD, 509 with a physical disability, 129 with visual impairment, and 237 with hearing impairment as their primary type of need.

The three largest groups in special schools are children and young people with: autistic spectrum disorder (379); severe learning difficulties (333); and moderate learning difficulties (313).

Table 13 presents a higher total of **20,656 school pupils**, presumably because it includes children with EHC plans as well. West Sussex appears to have a slightly higher rate than the region and England overall - 17.2% of the school population compared with 15.2% regionally and 15.4% nationally.

While the SEN figure is higher than the FRS based estimate (Table 2), it should be noted that there will be children and young people covered by SEN/EHC plans who do not have a disability, although there will also be some children and young people with disabilities who are not covered by SEN/EHC plans.

**Table 12: All school pupils in West Sussex with special educational needs by primary type of need, January 2015**

Primary type of need	Primary school	Secondary school	Special school	All schools
Specific learning difficulty	1,323	1,752	16	3,091
Moderate learning difficulty	1,552	1,345	313	3,210
Severe learning difficulty	36	22	333	391
Profound and multiple learning difficulty	12	5	103	120
Social, emotional and mental health	1,197	1,234	205	1,440
Speech, language and communications needs	2,511	1,088	182	3,781
Hearing impairment	108	122	7	237

Visual impairment	60	66	3	129
Multi-sensory impairment	17	6	0	23
Physical disability	232	186	91	509
Autistic spectrum disorder	355	291	379	1,025
Other difficulty/disability	398	536	43	977
SEN support but no specialist assessment of type of need	173	182	0	355
<b>Total</b>	<b>7,974</b>	<b>6,835</b>	<b>1,677</b>	<b>16,486</b>

Source: Department for Education

**Table 13: Number of pupils with Special Educational Needs (SEN), based on where the pupil attends school (2) (3) – January 2015**

ALL SCHOOLS (1):							
	Total Pupils	Pupils with statements or EHC plans (4)		Pupils with SEN support (4)		Total pupils with SEN	
		Number	% (5)	Number	% (5)	Number	% (5)
West Sussex	120,340	3,538	2.9	17,118	14.2	20,656	17.2
South East (6)	1,366,780	40,035	2.9	167,695	12.3	207,735	15.2
England (6)	8,438,145	236,165	2.8	1,065,280	12.6	1,301,445	15.4

(1) Includes middle schools as deemed.

(2) Includes all primary academies, including free schools.

(3) Includes pupils who are sole or dual main registrations.

(4) Education, Health and Care (EHC) plans were introduced from September 2014 as part of a range of SEND reforms. From 2015 SEN support replaces school action and school action plus but some pupils remain with these provision types in first year of transition.

(5) Expressed as a percentage of the total number of pupils in all schools.

(6) National and regional totals and total SEN across Local Authorities have been rounded to the nearest 5. There may be discrepancies between totals and the sum of constituent parts.

Source: School Census

The number of pupils with Statements of SEN or EHC plans has risen slowly from 3,213 in 2011 to 3,538 in 2015, although the current rate is similar to that for the region, and only slightly above the rate for England.

### 3.1 Hospital admissions

West Sussex had 89 emergency hospital admissions for asthma in young people aged 10 to 18 years in 2012/13, 48 for epilepsy and 94 for diabetes. Table 14 indicates that while asthma rates and epilepsy are below the rates for England, hospital admission rates for diabetes are considerably higher.

**Table 14: Hospital admissions for long term conditions in children and young people aged 10-18 years**

	Asthma (rate per 100,000 population) (2012/13)	Epilepsy (rate per 100,000 population) (2012/13)	Diabetes (rate per 100,000 population) (2012/13)
West Sussex	107.3	57.8	113.3
South East	99.2	53.0	93.3
England	122.0	57.9	96.4

Source: *Hospital Episode Statistics (HES)*, Health & Social Care Information Centre

## 4 Outcomes for children and young people with disabilities

Children and young people experience worse outcomes than the general population in many spheres of their lives. For example, national research evidence has found poor outcomes facing children and young people with disabilities in the following areas:

- Disabled children and young people currently face multiple barriers which make it more difficult for them to achieve their potential, to achieve the outcomes their peers expect and to succeed in education.
- 29% of disabled children nationally live in poverty.
- The educational attainment of disabled children is lower than that of non-disabled children.
- Disabled young people aged 16-24 are less satisfied with their lives than their peers and there is a tendency for support to fall away at key transition points as young people move from child to adult services.
- Families with disabled children report particularly high levels of unmet needs, isolation and stress.
- Following transition from a residential school, young people may experience good access to frontline health and social services, but also very few opportunities to enter employment or further education; no additional improvements in communication, self-care, or behaviours that challenge; a reduction in good support

for behaviours that challenge and increased reliance on restrictive practices; limited access to specialist services; and living at distance from the family home<sup>23</sup>.

- Over a third of children and young people with an identified learning disability also have a diagnosable psychiatric disorder<sup>24</sup>. According to the Joint Commissioning Panel for Mental Health (2013)<sup>25</sup> the expected prevalence of mental disorders in children with a learning disability is 36%.
- Children and young people with physical disabilities are twice as likely to develop psychological problems as those without, as are those who experience serious or chronic illness<sup>26</sup>.
- Children who have a limiting illness are more likely to be overweight or obese, particularly if they also have a learning disability. National data<sup>27</sup> show that 40% of children aged under-8 with a limiting illness and learning disability are obese or overweight, compared to 22.4% of children who have neither condition. This figure increases to almost 45% in the 8 to 13 age group of children with a limiting illness and learning disability.
- Children with disabilities are also identified in NICE guidance<sup>28</sup> as a group who are unlikely to participate in at least one hour of moderate to vigorous physical activity a day and therefore should be considered as part of any physical activity plans.
- Children with physical or learning disabilities have been identified by NICE as being at risk of not being fully immunised. NICE recommends that access to immunisation services should be improved for those with transport, language or communication difficulties and those with physical and learning disabilities<sup>29</sup>.
- Families with a disabled child are less likely to be living in a decent home compared to families with a non-disabled child. Those with a disabled child are 50% more likely than other families to live in overcrowded accommodation, to rate their home as being in a poor state of repair, and to report problems with wiring, draughts and damp in the child's bedroom.
- Compared to other groups of disabled people, disabled children requiring specifically adapted homes are the least likely to be living in suitable accommodation. All disabled children and their families, not just children with physical disabilities, are likely to experience difficulties with their housing<sup>30</sup>.
- Reports indicate that 80% of children with learning difficulties; 70% of children with autism; and 40% of children with speech and language difficulties are bullied and/or victimised.
- Young people with vision impairment are twice as likely (44%) as their sighted peers not to be in employment, education or training (NEET).

<sup>23</sup> Gore N et al (2015) *Residential school placements for children and young people with intellectual disabilities: Their use and implications for Adult Social Care*, NIHR SSCR Scoping Review

<sup>24</sup> Emerson and Hatton. 2007. *The Mental Health of Children and Adolescents with Learning Disabilities in Great Britain*. Lancaster: Institute for Health Research, Lancaster University

<sup>25</sup> Guidance for commissioning public mental health services. Updated July 2013. Available from: [www.jcpmh.info/resource/guidance-for-commissioning-public-mental-health-services/](http://www.jcpmh.info/resource/guidance-for-commissioning-public-mental-health-services/)

<sup>26</sup> Parry-Langdon (ed.). 2008. *Three Years On: Survey of the development and emotional well-being of children and young people*. Cardiff: ONS.

<sup>27</sup> Disability and obesity: the prevalence of obesity in disabled children, ChiMat 2011

<sup>28</sup> NICE January 2009 PH17 Promoting physical activity for children and young people <http://guidance.nice.org.uk/PH17>

<sup>29</sup> NICE PH21 reducing the difference in the uptake of immunisations recommendation 5

<sup>30</sup> Joseph Rowntree Foundation June 2008 Housing and disabled children: round up

- At age 26, disabled people were nearly four times as likely to be unemployed or involuntarily out of work than non-disabled people<sup>31</sup>.
- The prevalence of severe disability is increasing. This may be linked to the fact that more children and young people with profound disabilities and long-term conditions are living longer and surviving into adulthood<sup>32</sup>.

Research by Emerson and Hatton found that children who are already at risk of disability as a result of a range of physical and cognitive impairments are more likely than other children to live under conditions that impede development, increase the risk of poor health and (additional) disability and increase the risk of social exclusion<sup>33</sup>.

## 5 Concluding remarks

This report brings together a range of data and evidence about children and young people with disabilities in West Sussex.

There are a range of approaches to estimating the numbers which vary between a low of 4,628 (ChiMat) to a high of over 32,600 (also ChiMat). In the middle is our estimate of 15,072 based on Family Resources Survey prevalence rates for those aged 0-24 years old which we consider to be the most reliable.

In terms of future numbers, three clear trends emerge:

- Total numbers of children and young people with a disability are projected to increase by 8.6% between 2015 and 2035, reflecting the overall projected growth of the population in West Sussex over that period.
- The numbers of children and young people with ASD are predicted to increase steadily, reflecting better diagnosis due to increased public and medical awareness.
- Continuing developments in medical technology mean that the number of children living through birth and early years with complex needs is increasing. This not only means there is a greater number of children and young people who are in need of a social care intervention, but also that the complexity of the care need is greater.

These trends will put growing pressure on services and budgets over the next 15 to 20 years if there is no change in the pattern and character of service provision.

The research evidence on the outcomes of children and young people with disabilities clearly indicates that along the life pathway they experience poorer outcomes than the general population. In terms of their health, housing, economic, employment and social outcomes, children and young people with disabilities have

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<sup>31</sup> Burchardt T (2005) *The education and employment of disabled young people: Frustrated ambition*, Policy Press.

<sup>32</sup> Contact a Family (2006) 'About Families with Disabled Children – UK'

<sup>33</sup> Emerson, E., Hatton, C. (2007) [The socio-economic circumstances of children at risk of disability in Britain](#) in: *Disability and Society*. 22, 6, pp. 563-580.

poorer outcomes than their peers. There is an ongoing need for commissioners to find ways to improve these outcomes.

## Appendix I

## Children and young people aged 0-24 in West Sussex projected to have a disability by district and age quintiles, 2015-2035

Council area	Age quintile	2015	2020	2025	2030	2035
Adur	0-4	110	107	105	104	104
	5-9	181	189	185	183	181
	10-14	252	299	312	307	303
	15-19	236	223	261	270	267
	20-24	255	240	227	261	271
Arun	0-4	237	237	235	234	237
	5-9	551	586	585	582	578
	10-14	577	652	691	691	686
	15-19	540	519	586	618	619
	20-24	679	652	623	705	739
Chichester	0-4	179	180	179	178	179
	5-9	442	469	470	469	466
	10-14	455	519	548	549	547
	15-19	451	418	472	498	500
	20-24	565	556	526	593	621
Crawley	0-4	251	247	242	239	242
	5-9	546	579	573	562	557
	10-14	505	611	648	642	631
	15-19	425	429	514	541	537
	20-24	576	555	546	633	666
Horsham	0-4	213	211	211	208	207
	5-9	550	551	548	547	541
	10-14	633	693	701	699	697
	15-19	549	509	563	571	570
	20-24	501	464	434	484	501
Mid Sussex	0-4	254	251	249	245	243
	5-9	629	644	639	635	626
	10-14	683	760	781	777	773

Council area	Age quintile	2015	2020	2025	2030	2035
	15-19	582	565	630	646	645
	20-24	531	506	484	541	564
Worthing	0-4	185	183	182	180	181
	5-9	443	444	440	436	433
	10-14	440	508	512	508	504
	15-19	393	379	436	441	439
	20-24	474	458	439	501	515

*Figures calculated using prevalence rates of 3% for age 0-4, 7% for 5-10, 8% for 11-14, 7% for 15-19 and 9% for 20-24 from FRS 2011/12.*



## Appendix II

### People aged 18-64 predicted to have a learning disability, by age in West Sussex

People predicted to have a learning disability	2015	2020	2025	2030
18-24	1,543	1,455	1,460	1,627
25-34	2,298	2,343	2,321	2,229
35-44	2,549	2,547	2,656	2,724
45-54	2,853	2,784	2,616	2,633
55-64	2,308	2,630	2,863	2,793
Total population aged 18-64 predicted to have a learning disability	11,553	11,759	11,917	12,006

Figures may not sum due to rounding. Crown copyright 2014.

### People aged 18-64 predicted to have a moderate or severe learning disability, and hence likely to be in receipt of services, by age in West Sussex

People predicted to have a moderate or severe learning disability	2015	2020	2025	2030
18-24	357	339	345	388
25-34	494	504	499	479
35-44	641	641	669	687
45-54	640	625	590	599
55-64	501	572	618	599
Total population aged 18-64	2,634	2,680	2,720	2,751

Figures may not sum due to rounding. Crown copyright 2014

These predictions are based on prevalence rates in a report by Eric Emerson and Chris Hatton of the Institute for Health Research, Lancaster University, entitled Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England, June 2004. The authors take the prevalence base rates and adjust these rates to take account of ethnicity (i.e. the increased prevalence of learning disabilities in South Asian communities) and of mortality (i.e. both increased survival rates of young people with severe and complex disabilities and reduced mortality among older adults with learning disabilities). Therefore, figures are based on an estimate of prevalence across the national population; locally this will produce an over-estimate in communities with a low South Asian community, and an under-estimate in communities with a high South Asian community.

## Appendix III

### Number and percentage of *primary* school pupils with special educational needs (SEN) by primary type of need, January 2015

Primary type of need	West Sussex number	West Sussex %	South East %	England %
Specific learning difficulty	1,323	16.6	13.5	10.5
Moderate learning difficulty	1,552	19.5	23.1	24.6
Severe learning difficulty	36	0.5	0.6	0.9
Profound and multiple learning difficulty	12	0.2	0.2	0.3
Social, emotional and mental health	1,197	15	16.4	15.6
Speech, language and communications needs	2,511	31.5	27.5	27.7
Hearing impairment	108	1.4	1.6	1.7
Visual impairment	60	0.8	0.9	1.0
Multi-sensory impairment	17	0.2	0.2	0.2
Physical disability	232	2.9	2.9	3.0
Autistic spectrum disorder	355	4.5	6.8	6.5
Other difficulty/disability	398	5	3.8	4.4
SEN support but no specialist assessment of type of need	173	2.2	2.5	3.6
Total (count)	7,974			

Source: Department for Education

Number of pupils by their main need expressed as a percentage of all pupils with a type of need provided

**Number and percentage of secondary school pupils with special educational needs (SEN) by primary type of need, January 2015**

Primary type of need	West Sussex number	West Sussex %	South East %	England %
Specific learning difficulty	1,752	25.6	24.9	20.9
Moderate learning difficulty	1,345	19.7	21.5	24.9
Severe learning difficulty	22	0.3	0.3	0.6
Profound and multiple learning difficulty	5	0.1	0.0	0.1
Social, emotional and mental health	1,234	18.1	19.9	19.3
Speech, language and communications needs	1,088	15.9	10.5	9.8
Hearing impairment	122	1.8	2.1	2.3
Visual impairment	66	1.0	1.3	1.3
Multi-sensory impairment	6	0.1	0.1	0.1
Physical disability	186	2.7	2.9	3.0
Autistic spectrum disorder	291	4.3	9.4	8.3
Other difficulty/disability	536	7.8	5.8	6.8
SEN support but no specialist assessment of type of need	182	2.7	1.2	2.4
Total (count)	6,835			

Source: Department for Education

Number of pupils by their main need expressed as a percentage of all pupils with a type of need provided

**Number and percentage of *special* school pupils with special educational needs (SEN) by primary type of need, January 2015**

Primary type of need	West Sussex number	West Sussex %	South East %	England %
Specific learning difficulty	16	1.0	1.1	1.3
Moderate learning difficulty	313	18.7	18.2	16.2
Severe learning difficulty	333	19.9	20.8	24.4
Profound and multiple learning difficulty	103	6.1	6.3	8.6
Social, emotional and mental health	205	12.2	13.7	13.0
Speech, language and communications needs	182	10.9	8.3	5.5
Hearing impairment	7	0.4	1.9	1.3
Visual impairment	3	0.2	0.3	0.7
Multi-sensory impairment	x	x	0.2	0.2
Physical disability	91	5.4	3.5	3.5
Autistic spectrum disorder	379	22.6	24.5	24.0
Other difficulty/disability	43	2.6	0.8	1.0
SEN support but no specialist assessment of type of need	0	0	0.6	0.2
Total (count)	1,677			

Source: Department for Education

Number of pupils by their main need expressed as a percentage of all pupils with a type of need provided - x = 1 or 2 pupils only