

This briefing incorporates work undertaken by the Institute of Public Care for West Sussex County Council as part of the needs assessment of people born with or who acquire a lifelong disability. Please contact [jacqueline.clay@westsussex.gov.uk](mailto:jacqueline.clay@westsussex.gov.uk).

## Purpose of Briefing

To provide an estimate of the number of children living in West Sussex who have a disability; provide age specific estimates, outline the sources of data and background to the assumptions made. This information is important to aid the planning of services and support to children, young people and their families.

## What is the Issue?

There is no single definition of disability and therefore providing a single accurate estimate is difficult; for example the 2011 Census<sup>1</sup> definition of disability is: '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'; the Family Resources Survey (FRS) uses a different definition: 'a long-standing illness, disability or impairment which causes substantial difficulty with day-to-day activities'. Estimating the number of children and young people according to "severity" or in terms of specific needs or conditions is also problematic. This briefing provides the background to the basis estimates have been made.

## Why is this important?

Children and young people with a disability may need additional services and support to achieve their potential and enjoy life. Delivering current services, and planning for the future, requires managers to have an understanding of the total number of people in the local population who have a disability.

## What do we know?

- **OVERALL DISABILITY - Using FRS Definition**

Using age-related prevalence rates, there are estimated to be nearly 15,100 children and young people with a disability aged 0-24 years in West Sussex in 2015, projected to increase to 16,400 (8.6%) in the next 20 years. The increase in numbers aged 10-14 and 15-19 years old is projected to be the greatest (17% and 13% respectively). Increases are based on population change, not a projected change in prevalence assumptions.

Age	2015	2020	2025	2030	2035	2015-35 % change
0-4 years	1,430	1,415	1,405	1,390	1,395	-2.5%
5-9 years	3,340	3,460	3,440	3,415	3,380	1.2%
10-14 years	3,545	4,040	4,195	4,175	4,140	16.8%
15-19 years	3,175	3,040	3,460	3,585	3,575	12.6%
20-24 years	3,580	3,430	3,280	3,720	3,875	8.3%
<b>Total</b>	<b>15,075</b>	<b>15,395</b>	<b>15,775</b>	<b>16,280</b>	<b>16,370</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.*

- **CHILDREN AND YOUNG PEOPLE WITH A “SEVERE” DISABILITY**

There are significant differences in the estimates for the numbers of children and young people with severe disabilities in West Sussex. While one source (1) estimates that there are 130 children and young people living with a severe longstanding illness or disability aged 0-19 years old ; another generates an estimate of 860 with a severe learning difficulty aged 0-19 years old and 210 with a profound and multiple learning difficulty aged 0-19 years old.

- **NUMBER OF CHILDREN WITH A LEARNING DISABILITY**

The main source of information is via school SEN data. However as this information is collected via schools, it does not include pre-school aged children and relates to the school based population not the resident population.

*Population based estimates*

Using national research (2), the table below produces estimates using a prevalence assumptions of 0.39% of girls aged 2 years or under, and 0.60% of boys at the same age, this assumes that in pre-school age children only those with a profound or severe learning disability is likely to be identified and so reflects the prevalence of these children in later years.

**Children Aged 0-17 years with a Learning Disability - Resident in West Sussex (2014 Population)**

Age (years)	Boys	Girls	Total	Prevalence Assumption	
				Girls	Boys
0-1	55	35	90	0.4%	0.6%
2-3	180	105	285	1.1%	1.7%
4-5	295	170	465	1.8%	2.9%
6-7	400	235	635	2.5%	4.0%
8-9	380	220	600	2.5%	4.0%
10-11	375	210	585	2.5%	4.0%
12-13	360	210	570	2.5%	4.0%
14-15	385	220	605	2.5%	4.0%
16-17	400	225	625	2.5%	4.0%
<b>Total 0-17 years</b>	<b>2,830</b>	<b>1,630</b>	<b>4,460</b>		

*School derived estimates*

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.

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. Numbers are not projected to increase greatly in future years.

There are an estimated 120 people with Down’s Syndrome aged 0-24 years old in the county. Numbers are not projected to increase greatly in future years.

- **NUMBER OF CHILDREN AND YOUNG PEOPLE WITH CHALLENGING BEHAVIOUR**

Based on national research an estimated 5-15% of children with a learning disability develop behaviour that challenges (3).

- **NUMBER OF CHILDREN AND YOUNG PEOPLE WITH LEARNING DISABILITIES WITH MENTAL HEALTH PROBLEMS**

Research (4) estimates that 36% of children and young people with learning disabilities will also have a mental health problem. In West Sussex this would equate to 1,600 children aged 0-17 years.

- **NUMBER OF CHILDREN AND YOUNG PEOPLE WITH A SENSORY IMPAIRMENT**

Over 450 children and young people are estimated to have some level of visual impairment in West Sussex (1): 110 children aged 0-16 years are estimated to be severely sight impaired or blind, and 40 young people aged 18-24 are predicted to have a severe visual impairment . 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).

There are an estimated 20 children aged 0-17 who are registered as hard of hearing (and this will rise to 20 in 2035) and 55 who are registered deaf in 2015. There were 80 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.

- **NUMBER OF CHILDREN AND YOUNG PEOPLE WITH AUTISM (ASD)**

Based on National Autistic Society data (5), there are an estimated 2,600 children and young people aged 0-24 years with autism in West Sussex in 2015, rising to 2,800 by 2030. In contrast, two different sources of administrative data indicate either 760 or 1,025 school pupils in West Sussex in January 2015 with ASD.

## **THE FUTURE**

While there may be some variation in the estimates of numbers, it is clear that numbers will increase at least in line with the overall 7% projected increase in the population aged 0-24 years old in the next 20 years. In addition, continuing developments in medical technology mean that the number of children living through birth and early years is increasing, resulting in a growing number with complex needs. This not only means that there is a greater number of children and young people with disabilities 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.

## **How do we compare?**

This briefing, in the main, uses national research and applies findings from that research to the local population. Therefore it is not assumed that West Sussex has a higher, or lower, *prevalence* of disability than other areas (i.e. differences are due to population size).

## Contact and References

Drafted by Jacqueline Clay

Jacqueline.clay@westsussex.gov.uk

- (1) ONS / Family Fund Trust / ChiMat data accessed online via <http://atlas.chimat.org.uk>
- (2) *People with Learning Disabilities in England 2011* - Emerson et al (2012)
- (3) *Estimating the Number of Children in England with Learning Disability whose Behaviours Challenge* – Emerson et al(2014)
- (4) *The Mental Health of Children and Adolescents with a Learning Disability* - Emerson and Hatton (2007)
- (5)

**Public Health and Social Research Unit**

**West Sussex County Council**

[jsna.westsussex.gov.uk](http://jsna.westsussex.gov.uk)

---

i