

## 7.2.9 Children and young people with disabilities and complex health needs

### Why is this issue important?

The 2010 Equality Act defines disability as “a physical or mental impairment that has a ‘substantial’ (completing a task takes much longer than it usually would) and ‘long-term’ (12 months or more) negative effect on ability to do normal daily activities”.<sup>1</sup> Children with complex health needs are defined as either children with severe and multiple impairments or children who require support from a complex network of agencies.<sup>2</sup>

National estimates suggest that around 7% of those aged 0-19 have a disability.<sup>3</sup> This equates to 908,500 0-19 year olds in England or 148,400 in the South East.<sup>4</sup> Currently 14.4% of school aged children are identified as having Special Educational Needs (SEN).<sup>5</sup> National research suggests approximately 1 in 100 children have autism spectrum condition (ASC)<sup>6</sup> and an estimated 355,200 children in England have a learning disability.<sup>7</sup>

People with physical and learning disabilities are more likely to suffer discrimination, poor access to some health services and worse employment prospects as a result of their disabilities, and these factors all impact negatively on their health.<sup>8</sup>

Compared with their peers, children and young people who are disabled or who have a Statement of SEN or Education Health and Care (EHC) plan (2.8% of the pupil population<sup>5</sup>) are considerably less likely to achieve well at school and are four times less likely to participate in higher education. Pupils with SEN are more than twice as likely to be

eligible for free school meals as their peers (27% compared to 12%). Pupils with SEN without a statement are 8 times more likely to receive a permanent exclusion than pupils with no identified SEN.<sup>5</sup> Looked after children are three-and-a-half times more likely to have SEN compared with all children.<sup>9</sup>

Nationally 26% of pupils with a statement or EHC plan have Autistic Spectrum Disorder listed as their primary type of need, making this the most common type of need. This is a 6% increase from 2011.<sup>5,10</sup>

The Department for Education (DfE)<sup>11</sup> has stated that:

- 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
- 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
- Only 4% of disabled children are supported by social services
- The prevalence of severe disability is increasing.

National estimates suggest that 35-40% of children and young people with a learning disability are likely to have a mental health issue.<sup>12</sup>

Among those needing specially adapted housing, disabled children are least likely to be living in suitable housing compared to all other age groups

<sup>1</sup> Great Britain. Equality Act 2010. Chapter 15. London: stationary office.

<sup>2</sup> Centre for Excellence and Outcomes in Children and Young People's Services (2009) Disability: Progress map summary. June 2009. Improving the wellbeing of disabled children and young people through improving access to positive and inclusive activities. Department for Education

<sup>3</sup> Department of Work and Pensions, Family Resources Survey 2014/15

<sup>4</sup> Based on ONS national and sub-national Mid Year population estimates 2015 of 12,978,881 0-19 year olds in England and 2,119,761 0-19 year olds in the South East

<sup>5</sup> Department for Education: Special educational needs in England, January 2016

<sup>6</sup> Baird G, Simonoff E, Pickles A, Chandler S, Loucas T, Meldrum D, et al. Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *Lancet* 2006; 368: 210-5

<sup>7</sup> Emerson E, Hastings RP, McGill, P, Pinney, A, Shurlock, J, (2014) Estimating the Number of Children in England with Learning Disabilities and whose Behaviours Challenge

<sup>8</sup> Marmot, M. (2010). Fair society, healthy lives. The Marmot review Executive Summary. London: The Marmot Review.

<sup>9</sup> Department for Education. Support and aspiration: A new approach to special educational needs and disability (SEN Green Paper); 2011.

<sup>10</sup> Department for Education, Special educational needs in England: January 2011.

<sup>11</sup> National Child and Maternal Health Intelligence Network: Disability Needs Assessment, Brighton & Hove [Accessed 31/08/2016]

<sup>12</sup> Emerson, E. (2003) Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *Journal of Intellectual Disability Research*, 47, 51 -58.

## 7.2.9 Children and young people with disabilities and complex health needs

of disabled people, with less than half of disabled children (47%) living in suitable accommodation.<sup>13</sup>

National research identifies transport as a key issue, particularly in relation to extended services through the school system (getting to and from school and accessing clubs and leisure activities) with research showing 10% disabled young people believe transport is the greatest barrier to participation in sports events.<sup>14</sup> This is particularly pertinent due to the increase in the proportion of children who are overweight or obese, and the decrease of children participating in physical activity over the last two decades.

In addition to the needs of children and young people with disabilities there are wider implications for those caring for these children.

### Key outcomes

***The Brighton and Hove SEN Partnership Strategy 2013- 2017 published a series of high level outcomes with the following priorities:***

- ***We will improve outcomes and disadvantage for children and young people with SEN and disabilities***
- ***We will improve the assessment and identification of SEN and disabilities***
- ***We will create and ensure high quality provision for all children and young people with SEN and disabilities***
- ***We will work proactively and collaboratively with parents, children and families***
- ***We will improve transition arrangements post 16 and services for young people up to the age of 25***

### Impact in Brighton & Hove

Each local authority has a statutory responsibility to hold a register of children and young people with special educational needs and disabilities (SEND). In Brighton and Hove this is called Compass Brighton and Hove, and is administered by Amaze, a local parent carer support CVS organisation.

<sup>13</sup> Department of Communities and Local Government (2007) Housing in England 2005/06: a report principally from the Survey of English Housing 2005/06. London: DCLG.

<sup>14</sup> 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.

Registration on Compass Brighton and Hove is voluntary and there has been a steady increase in the number of registered children/young people with up-to-date records from 1,266 in 2008/09 to 1,927 in 2015/16. The upper age limit covered by the register increased 20 to 25 in late 2014, in line with changes to SEND legislation.

The associated incentive leisure card (Compass Card) means the voluntary register has a much higher sign-up than most local authority registers and also serves as a further incentive for families to update their children/young people's details every two years (the length of time a card runs for), so keeping the register up to date and relevant.

Families self-report the needs of their child/young person and the five highest reported groups of children/young people on the Compass are identified as having moderate learning difficulties (29%); moderate mobility problems (26.8%); severe challenging behaviour (25.1%), moderate challenging behaviour (23.7%) and severe learning difficulties (18.5%). Children/young people can have more than one of the needs above.

The most prevalent formal diagnoses on the Compass are: Autism Spectrum Condition (695), speech and language difficulties (664), moderate learning difficulties (558), anxiety (472), and emotional and behavioural difficulties (462).

Data from Compass Brighton and Hove indicates that:

24.6% of children/young people on the register have at least one sibling who also has SEND.

17% live in housing that their parent carer feels isn't adequate for the child/young person's needs.

48.5% of children/young people on the register have experienced bullying – either at or away from school.

In Brighton & Hove 1,560 under-16s were claiming DLA in November 2015 (12% of DLA claimants).<sup>15</sup>

Analysis by the Department for Education on January 2016 school census data shows that there were 6,156 pupils with an identified need (a Statement/Education, Health & Care Plan or SEN Support, previously called School Action and School

<sup>15</sup> Department for Work and Pensions.

## 7.2.9 Children and young people with disabilities and complex health needs

Action plus).<sup>16</sup> This amounts to 19.1% of the school population, compared to the national figure of 15.4%.<sup>17</sup>

Table 1 shows the percentage of pupils in this cohort by type of need identified. According to the Census, the percentage of children with an identified need of specific learning difficulty in the city (25.0%) is almost twice the national level (13.4%).

**Table 1: Percentage of pupils with an identified need by type of need, Brighton & Hove, January 2016**

SEN Description	%
Specific Learning Difficulty	25.0%
Speech, Language and Communication Needs	21.7%
Social, Emotional & Mental Health	18.3%
Moderate Learning Difficulty	13.1%
Autistic Spectrum Disorder	5.0%
SEN Support but no specialist assessment of type of need	4.3%
Other Difficulty/Disability	3.6%
Severe Learning Difficulty	2.7%
Physical Disability	2.6%
Hearing Impairment	1.9%
Visual Impairment	0.9%
Profound and Multiple Learning Difficulty	0.7%
Multi-Sensory Impairment	0.1%
Total	100%

**Source:** 2016 Schools Census, Brighton & Hove

The number of school age pupils with a statement of special educational need or an Education Health & Care plan have reduced slightly over the last few years, from 1,065 in 2009 (3.5% of the school population) to 941 in January 2016 (2.9%). Whilst this remains higher than the England average (2.8% of the school population) it needs to be noted that Brighton & Hove includes a proportionately high number of pupils in Brighton & Hove schools, in particular special schools, who have Statements from neighbouring authorities.<sup>18</sup>

<sup>16</sup> Brighton & Hove School data Service (2016) School Census Trend Report Summary Spring (January) 2016

<sup>18</sup> Brighton & Hove Council (2012) Special Educational Needs Annual Report 2011/12 March 2013

### Where we are doing well

The Child Development and Disability Service offers an integrated care pathway involving health, education and social care professionals in the assessment and management of children with disabilities.

The City Council residential care settings consistently achieve Outstanding Ofsted inspection ratings, for example Tudor House is rated Outstanding by Ofsted.

Community and Voluntary sector providers of short break services are of consistent high quality and are fully engaged in service developments.

A parent carer partnership charter has been developed by parents and service managers and is being used to 'star rate' the effectiveness of services at engaging with families.

Parent carers and other stakeholders are represented on all strategic groups and play an active part in the development of services both strategically and operationally. For example, the Disabled Children's and SEN Strategic Partnership Boards bring together all key stakeholders and parent carer representatives to review strategic developments across education, health and social care.

The Council now offers support in the form of Direct Payments in order for parents and carers to purchase respite via Personal Assistants. As part of this a new Resource Allocation tool is in use, which identifies needs and distributes resources more equitably.

Amaze drafted 301 Disability Living Allowance (DLA) and Personal Independence Payment (PIP) claims in 2015/16 via their Disability Living Allowance Service. They calculate the annual income generated from this project to be in excess of £2.5 million, with a further £1 million through passported benefits such as Carers Allowance.

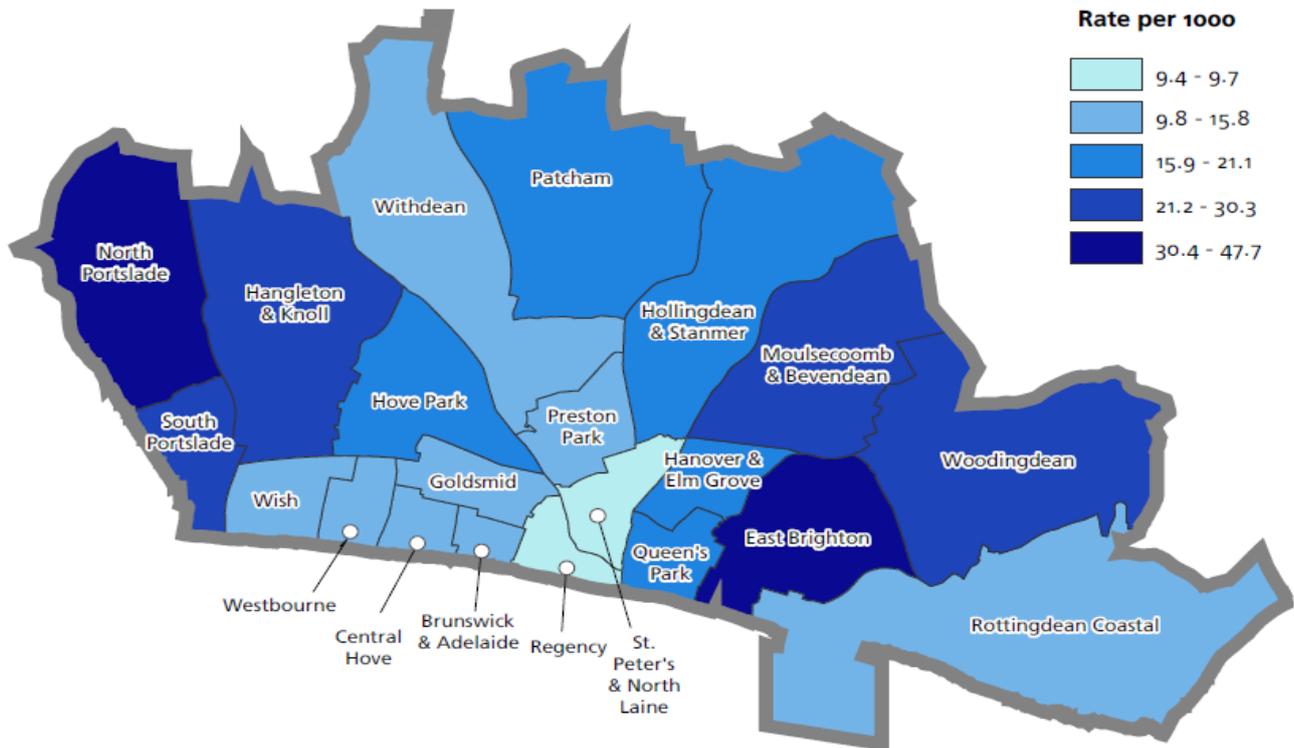
The Trust for Developing Communities (TDC) supports work with young people with disabilities. Its community groups in Hollingdean identified the need to improve facilities for children with disabilities and voted to fund a Sensory garden and

## 7.2.9 Children and young people with disabilities and complex health needs

accessible path for those with disabilities at Cherry Tree Nursery.<sup>19</sup>

**Figure 1: Children and young people aged 0-20 years registered on the Compass Database (rate per 1,000)**

represented in 0-19 year olds than are seen in the population of Brighton & Hove as a whole - with 18.1% BAME and 80.7 % White British compared to 21.7% BAME and 78.2% White British in 0-19 year olds across Brighton & Hove (from Census 2011).



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### Local inequalities

Of the 1,927 people registered on the Compass in 2015/16, the largest proportion (36.7%) is aged 11-16. However, over the last 2 years the biggest increase has been in those aged 20-25 years, (from 0% to 8.1%), with the register increasing the upper age limit from 20 to 25 in late 2014.

Extrapolation of national prevalence rates to Brighton & Hove suggest that children aged 0-4 years display lower prevalence of mild disability than children in the higher age groups, yet display a higher estimated prevalence of severe disability.

69.1% of children/young people on Compass Brighton and Hove are male, which is also seen in figures for disabled children/young people nationally.

Compass Brighton & Hove has slightly lower rates of Black, Asian or Minority Ethnic Groups (BAME)

In support of national findings, a large proportion of children/young people on Compass Brighton & Hove are in more deprived areas of the city (22.1% live in the East Brighton or Moulsecoomb & Bevendean wards, for example).

### Predicted future need

The Institute for Public Care Projecting Adult Needs and Service Information System (PANSI) is designed to look at how demography and certain conditions can impact on populations aged 18-64 years. Whilst there is no system for those under the age of 18, examination of PANSI projections for 18-24 year olds in the city help indicate the level of need of this cohort when they are in Children's Services. The evidence suggests that prevalence of many types of disability for those aged 18-24 will remain on or around current levels between 2015 and 2030.

<sup>19</sup> CTS Monitoring 2016. Call for Evidence 2016. TDC.

## 7.2.9 Children and young people with disabilities and complex health needs

### What we don't know

Compass Brighton and Hove is the primary data source for children with special educational needs and disabilities but it is a voluntary register.

Comparing Compass Brighton and Hove registrations with Disability Living Allowance take-up in the city, Amaze estimates that the register accounts for almost 70% of the children/young people who are eligible.

Local health data systems do not capture disability data in a way that helps predict future patterns of referral.

### Key evidence and policy

- The Care Act (2014)<sup>20</sup>
- The Disability Discrimination Act (2005)<sup>21</sup>
- The Children Act (2004)<sup>22</sup>
- SEND code of practice: 0 to 25 years (2014)<sup>23</sup>
- Equalities Act (2010)<sup>24</sup>
- The Children and Young Persons Act: the new short breaks duty (2008)<sup>25</sup>
- SEN green paper; Support and aspiration: A new approach to special educational needs and disability (2011)<sup>26</sup>
- 'Building the Right Support: A national plan to develop community services and close inpatient facilities for people with a learning disability and / or autism who display behaviour that challenges, including those with a mental health need.' NHS England 2015.

<https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

### Recommended future local priorities

1. Implementation of Resource Allocation tool, which identifies needs and distributes resources more equitably, in all cases.
2. Development of the single Education, Health and Care plan (EHCP) as per the SEN green paper ensuring plans are outcomes focused and child-centred and that services are jointly planned and commissioned.
3. Enhancement of early intervention services to prevent families reaching crisis point.
4. Development of parent information and support services to increase their resilience and wellbeing.

### Key links to other sections

- Child poverty
- Emotional health and wellbeing (children and young people)
- Carers

### Further information

Brighton & Hove Children and Young People with disabilities and/or complex health needs JSNA 2010  
<http://www.bhconnected.org.uk/content/needs-assessments>

Disability in Brighton & Hove, 2015

<http://www.bhconnected.org.uk/content/reports>

Brighton & Hove SEN Partnership Strategy 2012-2017, Brighton & Hove City Council

### Last updated

August 2016

<sup>20</sup> The Care Act 2014. Available at The National Archives: <http://www.legislation.gov.uk/ukpga/2014/23/contents> [Accessed 01/08/16]

<sup>21</sup> The Disability Discrimination Act 2005. Available at The National Archives: [www.legislation.gov.uk/ukpga/2005/13/contents](http://www.legislation.gov.uk/ukpga/2005/13/contents) [Accessed 22/08/16]

<sup>22</sup> The Children Act 2004. Available at The National Archives: <http://www.legislation.gov.uk/ukpga/2004/31/contents> [Accessed 31/08/2016]

<sup>23</sup> SEND code of practice: 0 to 25 years 2014. Available at: <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25> [Accessed 31/08/2016]

<sup>24</sup> Equalities Act 2010. Available at The National Archives: <http://www.legislation.gov.uk/ukpga/2010/15/contents> [Accessed 31/08/2016]

<sup>25</sup> The Children and Young Persons Act 2008. Available at: <http://www.legislation.gov.uk/ukpga/2008/23/contents> [Accessed 31/08/2016]

<sup>26</sup> SEN green paper 2011. Available at: <https://www.gov.uk/government/publications/support-and-aspiration-a-new-approach-to-special-educational-needs-and-disability-consultation>