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”. 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.

National estimates suggest that around 6% of those aged 0-19 have a disability. This equates to 762,600 0-19 year olds in England or 167,400 in the South East. Currently 19.8% of school aged children are identified as having Special Educational Needs (SEN). National research suggests approximately 1 in 100 children have autism spectrum condition (ASC) and an estimated 410,000 children have a learning disability.

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.

Compared with their peers, children and young people who are disabled or who have a Statement of SEN (2.8% of the pupil population) 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 (30% compared to 14%) and pupils at School Action Plus are 20 times more likely to receive a permanent exclusion than pupils with no identified SEN. Looked after children are three-and-a-half times more likely to have SEN compared with all children.

Nationally, the number of children whose statement lists autism as a primary need has increased by 5% since 2011, and for School Action Plus autism as a primary need has increased by 12%.

National estimates suggest that over 50% of children who have a disability live on or near the margins of poverty.

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

Among those needing specially adapted housing, disabled children are least likely to be living in suitable housing compared to all other age groups of disabled people, with less than half of disabled children (47%) living in suitable accommodation.

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. 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.

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4 Based on ONS national and sub-national Mid Year population estimates 2011 of 12,710,562 0-19 year olds in England and 2,079,025 0-19 year olds in the South East.
7.2.9 Children and young people with disabilities and complex health needs

In addition to the needs of children and young people with disabilities there are wider implications for those caring for these children. The unpaid carer population saves the UK an estimated £87 billion a year.\(^{15}\)

**Key outcomes**

The Brighton & Hove Child Development and Disability Strategy 2011 published a series of high level outcomes with the following commitments:

- **Parent carers will have easy access to the full range of opportunities and choices to maintain a good quality of life, having a life of their own, having a caring system on their side and being recognised as expert care partners.**

- **Children and young people with disabilities will receive services that meet their needs and aspirations**

**Impact in Brighton & Hove**

Application of national estimates of the prevalence of child disability to Brighton & Hove suggests a prevalence of between 3% (1,767) and 5.4% (3,181) of children and young people with disabilities in the city.\(^{16}\) However, literature suggests approximations are underestimates as not all children with disabilities and complex health needs are registered for Disability Living Allowance (DLA) or SEN. DLA provides a contribution towards the extra disability-related costs of severely disabled people under the age of 65 years.

Each local authority has a statutory responsibility to hold a register of disabled children. In Brighton & Hove this is The Compass database administered by Amaze, a local parent support CVS organisation. Registration on the Compass is voluntary and there has been a steady increase in the number of registered children with up-to-date records\(^{17}\) from 1,266 in 2008/09 to 1,526 in 2012/13. The associated incentive leisure/sporting card means the voluntary register has a much higher sign-up than most local authority registers.

Families self-report the needs of their child and the five highest reported groups of children on the Compass are identified as having moderate mobility problems (29.3%) moderate learning difficulties (26.9%), severe challenging behaviour (24.4%), moderate challenging behaviour (22.9%) and severe learning difficulties (19.5%). Children can have more than one of the needs above.\(^{18}\)

The most prevalent formal diagnoses on the Compass are: speech and language difficulties (462), Autism Spectrum Condition (421), moderate learning difficulties (410) and emotional and behavioural difficulties (348).\(^{16}\)

In Brighton & Hove 1,420 under-16s were claiming DLA in November 2012 (10% of DLA claimants).\(^{19}\) Amaze data indicates that of the families registered on the Compass that were supported by the charity’s DLA service in 2011/12 47% live entirely on benefits.\(^{20}\) Of those parents and carers using the Amaze DLA service in 2012/13:

- 27% have more than one disabled child;
- 44% are lone parent families\(^{18}\) with local research indicating that 70% of all lone parent households in the city are out of work.\(^{21}\)
- 18% have one or more parents with mental health problems.\(^{18}\)
- A quarter (24%) of parents caring for disabled children reported their housing is inadequate to meet their disabled child’s needs.\(^{20}\)

The number of school age pupils with statements of special educational need have reduced slightly over the last few years, from 1,065 in 2009 (3.5% of the school population) to 975 in 2012 (3.3%). 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.\(^{22}\)

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\(^{17}\) Total numbers on the database were 1,480 in 2008/09 and 1,908 in 2012/13 (figures in the main text are those children and young people with records updated in the last two years).

\(^{18}\) Amaze, Compass Database accessed 29th May 2013.

\(^{19}\) Department for Work and Pensions.

\(^{20}\) Amaze, Compass Database accessed 29th May 2013.

\(^{21}\) Amaze survey 2011.

Of those with statements, the most prevalent identified needs in 2012 were: Autistic Spectrum Condition (21%), Speech, language and communication difficulties (17%) and Behaviour, Emotional and Social Difficulties (14%).

Mascot are a parent-led voluntary group with over 130 members supporting families affected by Autistic Spectrum Condition (ASC) in Brighton & Hove. A 2012 Mascot survey of 77 local parents of young people with ASC looked at services and identified difficulties in: obtaining a statement (44%); the communication approach and strategy in mainstream schools (49%) and bullying of the young person (50%). There was also a recognised difficulty with obtaining an initial diagnosis (44%). However, parents reported a good/very good quality of teaching (72%) and teaching staff (75%) in schools. Just over half of this cohort reported that their family had a good/very good quality of life.

Analysis by the Department for Education on January 2013 school census data shows that there were 3,674 pupils with an identified need (a Statement or in the School Action Plus scheme). This amounts to 24.8% of the school population, compared to the national figure of 19.8%. 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 (21.2%) is twice the national level (10.8%). Source: 2013 Schools Census, Brighton & Hove

In 2012 34.3% of pupils with SEN were also eligible for Free School Meals (FSM)

The 2009 Mapping of youth activity for young people with disabilities in the city found the need for greater flexibility with transport to and from school clubs to be one of the main challenges for service provision for children with disabilities. In 2010, 23% of children on the Compass received transport services to school. Transport accessibility, availability and expense are common themes in local feedback from children and young people and their carers.

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.

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

<table>
<thead>
<tr>
<th>%</th>
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<tbody>
<tr>
<td>Speech, Language &amp; Communications Needs</td>
<td>25.6</td>
</tr>
<tr>
<td>Behaviour, Emotional &amp; Social Difficulties</td>
<td>20.8</td>
</tr>
<tr>
<td>Specific Learning Difficulty</td>
<td>21.2</td>
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<tr>
<td>Moderate Learning Difficulty</td>
<td>9.2</td>
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<td>Autistic Spectrum Disorder</td>
<td>6.8</td>
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<tr>
<td>Other Difficulty/Disability</td>
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<tr>
<td>Severe Learning Difficulty</td>
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<td>Physical Disability</td>
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<tr>
<td>Hearing Impairment</td>
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<tr>
<td>Visual Impairment</td>
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<td>Profound &amp; Multiple Learning Difficulty</td>
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<tr>
<td>Multi-Sensory Impairment</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
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Table 1: Percentage of pupils with statements of SEN or at School Action Plus by type of need

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23 Brighton & Hove City Council (June 2013) SEN resource manager
29 Amaze (2010) Compass database received and desired services
30 Brighton & Hove City Council and NHS Brighton and Hove (2010) JSNA Children and Young people with disabilities and complex health needs
7.2.9 Children and young people with disabilities and complex health needs

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.

In line with national guidance, there is an Individual budget pilot underway.

Amaze drafted 309 new or appeal DLA claims in 2012/13 as part of their Disability Living Allowance project, an increase of 9.6% on the previous year. They calculate the annual income generated from this project to be in excess of £2.3 million, with a further £1 million through passported benefits such as Carers Allowance.31

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

Local inequalities

Of the 1,526 people registered on the Compass in 2012/13, the largest proportion (46%) are aged 11-16. However, over the last five years the largest increase in registration has been in the under fives (11.5% in 2008/09 to 12.7% in 2012/13).32

Extrapolation of national prevalence rates to Brighton & Hove suggest that children aged zero to four years display lower prevalence of mild disability than children in the higher age groups, yet display a higher estimated prevalence of severe disability.33

Over two thirds of children and young people with disabilities are male (68%), and 15% are from a Black or Minority Ethnic group.34

In support of national findings, the greatest rates of those on the Compass are in more deprived areas of the city (Figure 1).

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32 Amaze. Compass statistics. 2012/13


34 Amaze. Compass statistics. 2012/13
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 2012 and 2020. However predictions are not yet available beyond 2020 due to ongoing incorporation of 2011 Census population updates, so indication of projected impact on children’s services is limited.

What we don’t know
The Compass is the primary data source for children with disabilities but as it is a voluntary database it does not contain full information regarding local equalities groups. There is no single reporting mechanism for disabled children. New national legislation governing disabled children – the Children and Families Bill – will require local authorities to plan services for disabled children from the age of 0-25. The Compass only records young people to the age of 19 and the Council is considering how this register can be extended.

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

Key evidence and policy
The local 2011 Child Development and Disability Strategy, took account of, amongst others:
- The Disability Discrimination Act (DDA) 2005
- The Children Act 2004
- SEN Code of Practice revised 2013
- Equalities Act 2010
- The Children and Young Persons Act 2008 : the new short breaks duty
- SEN green paper; Support and aspiration: A new approach to special educational needs and disability.

Recommended future local priorities
1. Implementation of the individual budgets pilot for social care short breaks and maintaining high quality services for those families not able or choosing an individual budget
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
www.bhlis.org/needsassessments
www.bhlis.org/children_and_young_people/

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