East Sussex Children and Young People with Special Educational Needs (SEN) or Disabilities (D)

Comprehensive Needs Assessment
Amendment and update to ASD information 2016

East Sussex Public Health Department
CONTENTS PAGE

1. Introduction
   1.1 Context
   1.2 Methodology
   1.3 Defining SEN and disability
   1.4 National SEN Policy
   1.5 Local Policy

2. National Context
   2.1 National Profile
   2.2 Determinants of Health
      2.2.1 Age
      2.2.2 Gender
      2.2.3 Ethnicity
   2.3 Type of Special Educational Need and Disability
      2.3.1 Physical Disability
      2.3.2 Autism Spectrum Disorder
      2.3.3 Behavioural, Emotional and Social difficulties
      2.3.4 Hearing Impairment
      2.3.5 Visual Impairment
      2.3.6 Multi-Sensory Impairment
      2.3.7 Learning Disability and Learning Difficulty
      2.3.8 Downs Syndrome
      2.3.9 Speech, Language and Communication Needs
      2.3.10 Congenital Abnormalities
   2.4 Health Needs
      2.4.1 Mental Health
      2.4.2 Community nursing
      2.4.3 Palliative Care
   2.5 Wider Determinants
      2.5.1 Poverty
      2.5.2 Social Inclusion
      2.5.3 Looked After Children
      2.5.4 Education
         2.5.4.1 Educational Attainment
         2.5.4.2 School Absence and Exclusions
      2.5.5 Not in Education, Employment or Training
      2.5.6 Further Education
      2.5.7 Transition
      2.5.8 Employment
      2.5.9 Housing
      2.5.10 Equipment and Environment
      2.5.11 Respite care
      2.5.12 Childcare
      2.5.13 Transport
      2.5.14 Lifestyle Factors
         2.5.14.1 Substance Misuse
         2.5.14.2 Obesity
         2.5.14.3 Sport and Leisure
   2.6 Families and Carers
   2.7 Summary of key national issues

3. Local Context
3.1 Local population

3.1.1 Poverty
3.1.2 Prevalence
3.1.3 Disability Living Allowance

3.2 Type of Special Educational Need and Disability

3.2.1 Downs Syndrome
3.2.2 Autistic Spectrum Disorder
3.2.3 Learning Difficulties

3.3 Health Needs

3.3.1 Maternal Age
3.3.2 Smoking
3.3.3 Low Birth weight
3.3.4 Breastfeeding
3.3.5 Palliative Care

3.4 Wider Determinants

3.4.1 Education

3.4.1.1 SEN provision in East Sussex
3.4.1.2 Attainment
3.4.1.3 Attendance
3.4.1.4 Exclusions
3.4.1.5 Home to School Transport

3.4.2 Not in Education, Employment or Training
3.4.3 Transition
3.4.4 Social care
3.4.5 Vulnerable Children

3.4.5.1 Children in Need
3.4.5.2 Child Protection
3.4.5.3 Looked After Children

3.5 Summary of key local issues

4. Projecting Future Need

4.1 Summary of Key future needs

5. Services in relation to need

5.1 How services are commissioned
5.2 Evaluation of SEND Pathfinder Programme
5.3 Children’s Disability Service

5.3.1 Service Satisfaction
5.3.1.1 Complaints

5.4 Health Services

5.4.1 Community Paediatric Services

5.4.1.1 Community Wellchild Nurse
5.4.2 Continuing Health Care
5.4.3 Personal Health Budgets
5.4.4 Palliative Care

5.4.4.1 Chestnut Tree House
5.4.4.2 Demelza
5.4.4.3 Chailey Heritage Clinical Services

5.4.5 Integrated Therapy Services

5.5 Autism Spectrum Disorder

5.6 Residential Care

5.6.1 Acorns and The Bungalow
5.6.2 Jemini Response
5.6.23 Mayfield Children’s Home
5.6.4 Greenacres

5.7 Equipment

5.8 Early Years

5.9 Keyworking
5.10 Team Around the Family
5.11 Inclusion Services
  5.11.1 Flexible Learning Educational Support Service
  5.11.2 Anti-Bullying Service
5.12 Children’s Centres
5.13 Childcare
5.14 Portage
5.15 Education
5.16 Transport
5.17 Transition
5.18 Self Directed Support and Personal Budgets
5.19 Vulnerable Children
  5.19.1 THRIVE
  5.19.2 Looked After Children
5.20 Short Breaks
5.21 Leisure Services
  5.21.1 i-go card
5.22 Obesity
5.23 Housing
5.24 Information and Advice
  5.24.1 Local Offer
  5.24.2 Information for Families
  5.24.3 Additional Resources
5.25 Summary of Services in relation to need
6. Child, Parents and Carers Voice
  6.1 Summary of Child Parent and Carer Voice
7. Views of Service Providers
8. Main Findings
9. Recommendations

Author: Miranda Scambl, Public Health Practitioner
1.1 Context
The Government’s Children and Family Bill is transforming the system for children and young people with Special Educational Needs (SEN) and disabilities (D) so that services consistently support the best outcomes for them. In East Sussex SEND is a key theme in joint commissioning between Local Authority and the Clinical Commissioning Groups and the legislation particularly requires this. The reforms required address the needs of children from 0-25 years. This needs assessment aims to bridge the nationally recognised gap in information on the needs of children and young people who have SEND, by collating and analysing both national and local information and data to create a more comprehensive picture of children and young people who are disabled and/or have a special educational need in East Sussex.

Children with special educational needs and disabilities are a diverse group, some require multiagency support across health, social services and education for highly complex needs, while others require much less support. The measure of a child’s vulnerability and resilience is determined by the complexity of their needs. In order to best invest resources for these children, young people and their families, it is necessary to understand these needs. The 2009 East Sussex needs assessment of children with long term conditions looked at information available specifically on asthma, epilepsy and diabetes. The intention is not to revisit this area but to refresh and confirm what East Sussex services can expect in terms of population size and age distribution and the level of severe and complex needs and disabilities.

1.2 Methodology
This needs assessment analyses the evidence available for children with disabilities within East Sussex County Council and health partners, combined with nationally published statistics and research materials. The evidence base looks at current literature and East Sussex intelligence about the prevalence and trends in special educational needs and/or disability in the county. Where possible it looks at the population of children and young people aged less than 25 years in line with the Children and Families Act 2013, although much of the available data relates to children and young people aged under 18/19 years.

The needs assessment has been completed during a challenging time, with changes in healthcare structures impacting on availability of information and the capacity for intelligence to be provided. However, information from a number of agencies and organisations has helped build a picture of this population and provided the evidence to identify current and future levels of need. This JSNA considers the health and social care needs of children and young people with:

- Physical disabilities
- Profound and multiple disabilities
- Complex health needs
- Special Educational Needs
- Severe Learning Disabilities
- Mild & moderate learning disabilities
- Autistic spectrum disorder

The needs assessment does include safeguarding, but does not look in detail at long term limiting illness, or chronic illness which is not linked to disabilities as these areas require a more detailed study than can provided by this assessment.

There were a number of learnings from this needs assessment which impacted on the completeness of the picture it aimed to build. Most notably:
The timetable for this needs assessment was relatively restricted to meet commissioning needs.

It was not possible to consult with schools within the scope of this needs assessment and it is strongly recommended that there is a need for consultation with education regarding the needs of children and young people with special educational needs or disabilities.

The scope of the needs assessment was very broad which affected the depth it was possible to examine within the timeframe.

The current reforms to service provision impacted on the availability and accessibility of some evidence.

Some of the findings of this needs assessment are currently being, or will be addressed by legislative reforms to service provision and as such this needs assessment represents a snapshot of the needs of children and young people with SEND in East Sussex. Where it is evident that the issues are being addressed by reforms in provision it has been stated within this needs assessment.

1.3 Defining Special Educational Needs (SEN)

The term Special Educational Needs (SEN) is often used to describe children with additional learning needs requiring special educational provision, yet this can hide the wide spectrum of need that exists. For example, some children with SEN will have complex needs which require longer term support – such as those with profound and multiple learning difficulties (PMLD), while others need temporary interventions to help address and overcome learning difficulties.1 This document recognises the broad range of needs covered by this “catch-all” term and that SEN are individual with interventions tailored according to specific needs. Within Education, SEN are defined under the SEN code of practice and the Education Act 2001:

**Definition of Special Educational Needs (Education Act 2001)**

Children have special educational needs if they have a **learning difficulty** which calls for **special educational provision** to be made for them.

Children have a **learning difficulty** if they:
- a) Have a significantly greater difficulty in learning than the majority of children of the same age; or
- b) Have a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for children of the same age in schools within the area of the local education authority
- c) Are under compulsory school age and fall within the definition at (a) or (b) above or would so do if special educational provision was not made for them.

Children must not be regarded as having a learning difficulty solely because the language or form of language of their home is different from the language in which they will be taught.

**Special educational provision** means:
- a) for children of two or over, educational provision which is additional to, or otherwise different from, the educational provision made generally for children of their age in schools maintained by the LEA, other than special schools, in the area

**Defining Disability**

There are a number of statutory definitions of disability used by central government, and no common definition is used across health, local authority or other relevant groups. Overall within health, the assumption is that the World Health Organization (WHO) definition is used:

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However, different bodies use different definitions including:

<table>
<thead>
<tr>
<th>Source</th>
<th>Definition</th>
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</thead>
<tbody>
<tr>
<td><strong>Disability Discrimination Act (DDA), 2005</strong></td>
<td>A physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities</td>
</tr>
<tr>
<td><strong>The Equality and Human Rights Commission (EHRC), 2007</strong></td>
<td>A condition affecting the body, perhaps through sight or hearing loss, a mobility difficulty or a health condition</td>
</tr>
</tbody>
</table>
| **The Equality Act (EA) 2010** | A person is disabled, if he or she has a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on his or her ability to do normal daily activities:  
  - ‘substantial’ is more than minor or trivial - e.g. it takes much longer than it usually would to complete a daily task like getting dressed  
  - ‘long-term’ means 12 months or more - e.g. a breathing condition that develops as a result of a lung infection |

Within the SEN code of practice, which details the requirements around special educational needs, a number of categories and types of special educational needs are used. While this is a proxy indicator for disability it is not a reliable indicator for severity of disability as it is not reflective of the spectrum of disability. There are three levels of intervention for children identified with SEN:

- **School Action** is when the school feels able to meet a child’s needs;
- **School Action Plus** is the level of intervention for a child where the school requires external support to meet the needs of the child;
- **Statement of SEN** is where a child’s needs require that the local authority sets out the support required in a statement, which they are required by law to ensure is then provided.

Within statements and school action plus, the child or young person will be identified as having a type of SEN. A minimum of a primary type of SEN is identified, but for those with complex needs, a secondary or tertiary SEN type can also be given. The SEN types are as follows:

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1 Department for Children, Schools and Families (2010) Breaking the link between special educational needs and low attainment Everyone’s business.
Table 1: Types of Special Educational Need

<table>
<thead>
<tr>
<th>SEN CODE</th>
<th>SEN TYPE</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD</td>
<td>Autistic Spectrum Disorder</td>
</tr>
<tr>
<td>BESD</td>
<td>Behavioural, Emotional and Social difficulties</td>
</tr>
<tr>
<td>HI</td>
<td>Hearing Impairment</td>
</tr>
<tr>
<td>MSI</td>
<td>Multi-Sensory Impairment</td>
</tr>
<tr>
<td>OTH</td>
<td>Other difficulty or disability</td>
</tr>
<tr>
<td>PD</td>
<td>Physical Disability</td>
</tr>
<tr>
<td>MLD</td>
<td>Moderate Learning Difficulty</td>
</tr>
<tr>
<td>PMLD</td>
<td>Profound and Multiple Learning Difficulty</td>
</tr>
<tr>
<td>SLCN</td>
<td>Speech, Language and Communication Needs</td>
</tr>
<tr>
<td>SLD</td>
<td>Severe Learning Difficulties</td>
</tr>
<tr>
<td>SpLD</td>
<td>Specific Learning Difficulty</td>
</tr>
<tr>
<td>VI</td>
<td>Visual Impairment</td>
</tr>
</tbody>
</table>

However, the Children and Families Bill is currently going through parliament and will reform the system for special educational needs so that statements and school action/school action plus are replaced with an Education, Health and Care Plan. This will include offering families personal budgets so that they have more control over the support they need. East Sussex is part of South East 7 (SE7) Consortium which includes: Brighton & Hove; East Sussex; Hampshire; Kent; Medway; Surrey; and West Sussex. SE7 is one of the 20 pathfinders who have been piloting these new reforms since September 2011.

1.4 National SEND Policies
There is a growing body of evidence regarding outcomes for disabled young people which has meant that improving their health and wellbeing is a government priority, as illustrated in policies such as the National Service Framework for Children, Young People and Maternity Services (DH/DfES, 2004), A Transition Guide for all Services (DCSF/DH, 2007), Transition: Moving on Well (DH, 2008), and the Aiming High for Disabled Children Transition Support Programme (HM Treasury and DfES, 2007). Local Authorities are currently required to publish over 17 information documents regarding SEN provision within the school setting, including, for example: a policy statement by the authority on their general approach to SEN;

- details of funding for children with SEN;
- transport services for children with SEN or disabilities;
- guidance for parents who suspect their child may have special educational needs.

There are no specific duties on local authorities specifically to provide information regarding services for young people, although local authorities are under a duty to encourage, enable or assist the effective participation of young people in education and training.  

The 2013 Children and Families Bill is reforming the systems for adoption, looked after children, family justice and special educational needs. The Bill represents the biggest reforms of SEN provision ever, extending the SEN system from birth to 25, giving children, young people and their parent’s greater control and choice in decisions and ensuring needs are properly met. It takes forward the reform programme set out in “Support and aspiration. A new approach to special educational needs and disability: Progress and next steps” by:

1. New joint-arrangements for assessing, planning and commissioning services for children and young people with special educational needs, which make it clear what will be offered, and who will deliver and pay for it, underpinned by a process to swiftly resolve local disputes between partners.

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1 Department for Education (March 2013) Evidence Pack Special Educational Needs: Children and Families Bill 2013
2. A new **local offer**, so children, young people and their families are clear what is available locally, with a clear complaint process and redress system. This is a new approach to information delivery in partnership with carers and young people, providing transparent and clear information across education, health and care.

3. Introduction of **local Education, Health and Care (EHC) Plans** from 0 to 25 which set out in one place the support from education, health and care services children and young people will receive; with a focus on helping to improve outcomes, including future employment and independent living.

4. **Personal budgets** for those families who want to have them.

5. A **duty on clinical commissioning groups (CCGs)** (and in limited cases, the NHS Commissioning Board) as health commissioners to secure the provision of health services which they have agreed in the EHC plan, similar to the duty on local authorities in respect of special educational services.

The reforms offer a whole new system of provision, providing greater opportunity for joint commissioning and culture change. They support, greater integrated working and greater choice and control for young people, their families and their carers.

The Children and Families Bill does not include disabled children without SEN, as the Government argues that most disabled children do have SEN, and those who do not are covered by the Equality Act and social care legislation. The 2011 Green Paper ‘**Support and aspiration: A new approach to special educational needs and disability**’, set out the Government’s vision of a radically different system by testing a range of proposals designed to respond to existing issues and gaps within the system. East Sussex is part of the SEND pathfinder programme and is tasked with: designing new arrangements to pilot and test how well they work in practice to better support life outcomes for children and young people; giving parents confidence by giving them more control; and transferring power to professionals on the front line and to local communities. The following table outlines the key dates for legislative reform with links to each relevant paper.

**Table 2: Timetable for Legislative Reform**

<table>
<thead>
<tr>
<th>Date</th>
<th>Progress</th>
</tr>
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<tbody>
<tr>
<td>March 2001</td>
<td>Special Educational Needs Code of Practice</td>
</tr>
<tr>
<td>March 2011</td>
<td>Green Paper (Support and aspiration: A new approach to SEND)</td>
</tr>
<tr>
<td>Sep 2011</td>
<td>Pathfinders launched</td>
</tr>
<tr>
<td>May 2012</td>
<td>Progress and Next Steps published</td>
</tr>
<tr>
<td>Dec 2012</td>
<td>Report of Education Select Committee</td>
</tr>
<tr>
<td>Dec 2012</td>
<td>Pathfinder Extension announced to September 2014</td>
</tr>
<tr>
<td>Feb 2013</td>
<td>First reading of the Bill</td>
</tr>
<tr>
<td>Spring 2013</td>
<td>Draft Regulations and Code of Practice</td>
</tr>
<tr>
<td>March 2013</td>
<td>Sen Evidence Pack published</td>
</tr>
<tr>
<td>May 2013</td>
<td>Council for Disabled Children announced as SEN and Disability Reform Partner</td>
</tr>
<tr>
<td>June 2013</td>
<td>Evaluation of the SEND pathfinder programme</td>
</tr>
<tr>
<td>Sept 2014</td>
<td>New legislation in force</td>
</tr>
</tbody>
</table>

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4 Secretary of State for Education (Feb 2013) Children and Families Bill 2013: Contextual Information and Responses to Pre-Legislative Scrutiny Presented to Parliament by the Secretary of State for Education by Command of Her Majesty February 2013: P62

5 The key changes between the draft SEN provisions and the Children and Families Bill have been outlined in a document produced by Council of Disabled Children in collaboration with Every Disabled Child Matters and the Special Education Consortium Feb 2013.

6 [http://www.sendpathfinder.co.uk/](http://www.sendpathfinder.co.uk/)

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4 [http://www.sendpathfinder.co.uk/](http://www.sendpathfinder.co.uk/)
The pathfinders will all test some core elements of reform, including:

- a single education, health and care plan from birth to 25 years old, focusing on whether outcomes for disabled children and their parents have been improved;
- personal budgets for parents of disabled children and those with SEN so they can choose which services best suit the needs of their children;
- strong partnership between all local services and agencies;
- improved commissioning, particularly through links to health reforms;
- role of voluntary and community sector organisations and parents in a new system;
- cost of reform.

1.5 Local SEND Policies

East Sussex is part of the pathfinder programme alongside other members of the South East 7 (SE7) Consortium which includes: Brighton & Hove; East Sussex; Hampshire; Kent; Medway; Surrey; and West Sussex.

Table 3: SE7 Framework for Assessment and Planning

| First Contact (needing help or support) | A family or practitioner who identifies that the child or young person has additional needs and may benefit from a single assessment and plan will inform a single contact who will arrange for a key worker to make contact with the parent carers. |
| listen and understand | The key worker will contact the family will help them to collate all the current assessment information. Any additional assessment information needed will be sought. All assessment information will be held jointly by the parent carer and the key worker. |
| agree and allocate | The parent carers, key worker with other relevant practitioners will agree the strengths, weaknesses and needs of the child or young person. Together they will agree the desired individual outcomes for the child and agree a priority for these. This information will Plan Review and learn provide the basis for the allocation of a personal budget, if appropriate. |
| plan | The parent carers, key worker and relevant practitioners develop a plan for the support that will be needed for the child or young person and their family to achieve the identified outcomes. The plan will set out accountabilities and timescales. It will be held jointly by the parent carer and the key worker. If a personal budget has been allocated the plan will set out how this will be used to add to the resources being used to support the child. |
| review and learn | The parent carers, key worker and relevant practitioners will agree how often the plan should be reviewed. It will be reviewed when there are any significant changes to the child or young person’s or their family’s situation. The plan will inform the development of an updated plan based on revised resource allocation as appropriate. If a personal budget is being used then review will include audit. |

East Sussex is the lead for special educational needs and disability work stream and has agreed to use regional principles to engage with families across the county and to use personalisation as an underpinning rationale for SEND reform. These legislative reforms to special educational needs and disability provision represent the greatest ever change to service provision, bringing a child and family centred approach to assessment and support, and ensuring they are fully involved in each stage. The reforms aim to make things simpler and more joined up so children, young people and their families participate in a streamlined assessment and planning process which brings the family and all the services together in assessing and monitoring the child’s progress.

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7 East Sussex County Council (2012) East Sussex SEND Pathfinder presentation
8 http://www.eastsussex.gov.uk/childrenandfamilies/specialneeds/sen/pathfinder/whatisthesendpathfinder.htm
By May 2012, approximately 70 families across the county were working with local partners to learn, experiment and develop a new system. Each Local Authority will be required to publish a “local offer” to: explain how they will: work with parents, local schools and colleges, as well as other services such as Health and Wellbeing Boards; encourage a more joined-up process when delivering services; describe any additional or different provision schools will make for children with SEN; and make the system less stressful for families by giving parents more information about the services and expertise available locally, increasing their choice.

The local offer sets out support in terms of the Whole System Quadrant (Figure 1) to give family options – for example, while they may not be eligible for certain options within targeted services, there are alternative support mechanisms available to them through universal services, social capital or community wealth, or self directed support. The draft local offer for East Sussex can be accessed at: http://www.se7pathfinder.co.uk/se7-local-offer. Core principles of the SE7 are of whole system support centring on family led principles and the child’s and family’s experiences:

**Figure 1: Whole System Support**

- Universal and mainstream services are usually the first place to look for opportunities for young people to get involved alongside their peers.
- Community wealth includes all the people community members know, and all the skills and knowledge represented by the community members, their assets, access and resilience.
- Sometimes there is an identified need such as a diagnosed health condition, or age group which needs targeted support such as Macmillan Nurses, special schools or a support service.
- Choice and control relates to personalised support including personal budgets and is for additional and individual support needs over and above those which can be met by other parts of the system.

In East Sussex the SEND pathfinder approach aims to relieve family anxiety by having clearer pathways to support, and to encourage young people with SEND to remain in education for longer. The challenge to this will be now looking at young people up to the age of 25 which involves straddling support with adult care and health services. In the local context the service provision has been developed incorporating:

- Testing out government proposals and informing the Children and Families Bill
- Developing a SEND code of practice
- Introducing school based plans for most SEND children by September 2014, written and reviewed by families and schools.
- Assessing children with the greatest level of need for an Education, Health and Care plan (EHCP) with children and their families fully involved in all stages of the process.
- Testing different versions of EHCPs locally to which there have been positive responses from parents and practitioners alike. A valued element is the “This is me” section which is designed to help children, their families and services to explore what the future might look like using pictures, words, photos, drawing etc, and also the circle of support that families can complete. Other sections will be completed by the local authority in the way statements currently are, except with the families and young people.

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9 East Sussex County Council  
10 South East 7 (Accessed August 2013) Special Educational Needs and Disability Website [http://www.se7pathfinder.co.uk/se7-local-offer](http://www.se7pathfinder.co.uk/se7-local-offer)  
11 In Control (2012) The SE7 Framework for Choice and Control  
12 East Sussex SEND Pathfinder Project manager
• Drafting of the local offer which will include everything from travel, leisure activities, training, work, social care services and independent living. The scope, content and quality of this offer will be extended to include all information by September 2014.
• Developing an online system to hold EHCPs and a new computer system to enable secure access to plans for families and practitioners can view all assessment information
• Exercising joint commissioning duties where integration of special educational provision with health and social care provision will promote wellbeing of children with SEN or improve quality of special educational provision. This includes joint commissioning for those with and without EHCPs, and for personal budgets.

Additional Relevant Local Policies and strategies
• Children and Young People's Plan (CYPP) The CYPP sets out how agencies will work more closely to support and improve the lives of children, young people and their families in East Sussex. https://czone.eastsussex.gov.uk/partnershipsinitiatives/cypp/Pages/main.aspx
• Early Help Strategy 2012-2015
• SEN transport policy 2012
• East Sussex Participation Strategy 2010-2013
• Autistic Spectrum Disorder Policy 2008
• Dyslexia Learning Friendly Policy 2009
• East Sussex Transition Strategy May 2009
2.1 National profile

The World Health Organization (WHO) estimates that childhood disability (0–14 years) affects 95 million (5.1%) children worldwide, of which 13 million (0.7%) have “severe disability”.[13] Current estimates suggest that there are 1.8 million children and young people up to the age of 25 in the UK with special educational needs, including just over 260,000 with high level needs and approximately 1.5 million with lower level SEN needs.[16] Using the Equalities Act definition of disability, research by the Department for Work and 2009/11 found that 9% of children aged 11-15 and 8% of young adults aged 16-24 in Great Britain were disabled. In the older age group, aged 16-24 8% were disabled.[15]

In January 2013, there were 230,000 pupils across all schools in England with statements of SEN, 2.8% of the population (which has remained unchanged over the last 5 years). The percentage of pupils with SEN without statements in all schools decreased from 17.0% in 2012 to 16.0% (1.3 million) in 2013, mainly in pupils at School Action. This figure has steadily decreased since 2010. The National Audit Office (NAO) estimates the amount spent on special education support to young people aged 16-25 to be around £640 million annually.[16]

The Department for Education (DfE) has stated that disabled children and young people face multiple barriers which hinder them from achieving the outcomes their peers can expect as:

- 29% of disabled children nationally live in poverty.
- The educational attainment of disabled children is lower than that of non-disabled children and fewer than 50% of schools have accessibility plans.
- Disabled young people aged 16-24 are less satisfied with their lives than their peers and support tends to fall away at key transition points between child to adult services.
- Families with disabled children report 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.

Research indicates that increased survival of babies born very prematurely has led to an increase in children with complex needs, yet there is little evidence to support this as most studies only look at three years follow-up and disabilities and educational difficulties may not become apparent until the child is older.[18,19] In 2011, three in every hundred disabled people were born with their impairment or health condition.[20]

The most common type of primary need for pupils with statements in January 2013 was autistic spectrum disorder (22%), and the least common was multi-sensory impairment (0.2%). Of those with School Action Plus, the most common types of need were behaviour, emotional and social difficulties (25%) moderate learning difficulty (23%) and speech, language and communication needs (22 %), with the least common being Profound and multiple learning disabilities (0.2%) and multi-sensory impairment (0.1%).[21]

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2.2 DETERMINANTS OF HEALTH

Research suggests that disability prevalence varies according to socio-economic background, with children from semi-skilled and unskilled manual families having a higher prevalence of both mild and severe disability than children from professional family backgrounds.22

- **Age:** There is a lower prevalence of disability in younger children which is likely to be due, in part to the later manifestation of a range of conditions, some conditions becoming more activity limiting as the child gets older23, and the high reliance on school Special Educational Needs (SEN) data which may miss children of preschool age.24 The latest national data suggests that younger children are more likely than older children to have speech, language and communication needs as their primary type of special educational need than older children. Older children between the ages of 11 and 15 years are more likely than younger children to have specific and moderate learning difficulties and behavioural, emotional and social difficulties. The percentage of pupils at primary schools with special educational needs with and without statements has been increasing steadily in each year group, while at secondary schools there has been a decrease in pupils with SEN without statements in each year group up to the age of 15. The percentage of pupils with statements remains approximately 2% across all ages.16

- **Gender:** Most surveys show that proportionately more boys than girls have long-standing illness or disability.25 Of the 10.6 million children with long term health problems or disabilities in England and Wales in 2011, 51% are boys and 49% girls.26 In January 2013, boys (2%) were two and a half times more likely than girls (0.8%) to have statements of SEN at state-funded primary schools and were nearly three times (2.8%) more likely than girls (1%) to have statements at state-funded secondary schools. There were also more boys than girls with special educational needs without statements in January 2013. Just under 21% of boys at primary schools and 21% at secondary schools were at School Action and School Action Plus compared to just over 11% of girls at primary schools and 13% at secondary schools.27

- **Ethnicity:** Nationally the percentages of disabled children by ethnic group fairly closely mirrors the percentages of children aged under 17 years by ethnic group in the population. However research suggests that there is a slightly lower percentage of White disabled children than might be expected, and a higher percentage of minority ethnic groups.28 According to the school SEN returns in January 2013, Black pupils were most likely and Chinese pupils least likely to have SEN, compared with pupils of other ethnic groups.29 Research suggests that some BME groups experience a disproportionately higher or lower rate of certain impairments, which may or may not be related to ethnicity. Poverty and social disadvantage appear to have a greater influence on the prevalence and impact of disability than ethnicity.30 Travellers of Irish heritage and Gypsy/Roma ethnicities have the greatest percentage of pupils with SEN, however due to the small numbers of these groups recorded these figures must be interpreted with caution.31

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29 Department for Education (July 2013) Special Educational Needs in England January 2013: Statistical first release
2.3 TYPE OF SPECIAL EDUCATIONAL NEED AND DISABILITY

2013 school census data indicates that in state-funded primary schools the three most frequent types of primary need are Speech, Language and Communication needs (31%), Moderate Learning Difficulty (20%) and Behaviour, Emotional & Social Difficulties (18%). In state-funded secondary schools these are Behaviour, Emotional & Social Difficulties (28%), Moderate Learning Difficulty (22%) and Specific Learning Difficulty (16%). In all special schools they are: Severe Learning Difficulty (25%), Autistic Spectrum Disorder (22%) and Moderate Learning Difficulty (18%) (Figure 2). This is consistent with findings from the 2012 school census.32

Figure 2: % of pupils by school and primary type of need January 2013

Source: Department for Education, 2013

2.3.1 Physical disability (PD)

A child or young person is considered to have a physical disability if they have a physical or mental impairment that has a significant or adverse effect on their day-to-day activities. Physical disability therefore covers a number of medical conditions including, for example: cerebral palsy, spina bifida, muscular dystrophy, and can include associated sensory impairments, neurological problems or learning difficulties. A medical diagnosis does not mean that the child or young person has SEN if they are able to access the curriculum and learn effectively without additional educational provision.33 The Thomas Coram Research Unit (TCRU) estimates that the mean percentage of disabled children in English local authorities is between 3% and 5.4%.34 The complexity of disability for some children can cause difficulty in multiple aspects of daily living, including: mobility; lifting and carrying; manual dexterity; continence; communication; memory, concentration and learning; recognising physical danger; and physical coordination. Analysis of the Family Resources Survey (2010) found that one third of disabled children (as defined by the Disability Discrimination Act) experience difficulties in two to four aspects of daily living.35

33 Department for Education and Skills (2005) Data Collection by Type of Special Educational Need
2.3.2 Autistic spectrum disorder (ASD)

The term autism describes a lifelong disorder where there are: “qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours”.\(^{36}\) ASD is a collective term that includes: Autism; atypical autism; and Asperger’s syndrome. Recent studies have shown that nearly three quarters of people with autism also meet diagnostic criteria for at least one other (often unrecognised) psychiatric disorder that is further impairing their psychosocial functioning, with Intellectual disability (IQ below 70) occurring in around half of all young people with autism.\(^{37}\) Some people with a diagnosis of autism will be able to live an independent life with little support, whilst for other people autism may be one of multiple disabilities that will require specialist support\(^{38}\).

Prevalence estimates for autism spectrum conditions have shown a steady increase over the past four decades\(^{39}\) from estimates for classic autism prevalence at 4 per 10,000 in 1978, to recent estimates of autism spectrum conditions (including classic autism) affecting approximately 1.16% of the population.\(^{40}\) These increases have been attributed to: improved recognition and detection; changes in study methodology; an increase in available diagnostic services; increased awareness among professionals and parents; growing acceptance that autism can coexist with a range of other conditions; and a widening of diagnostic criteria.\(^{41}\)

2.3.3 Behavioural, emotional and social difficulties

Pupils may be described as having behavioural, emotional and social difficulties (BESD) when their behaviour interferes with their own learning or that of others. Government guidance defines BESD as: “Pupils with behavioural, emotional and social difficulties cover the full range of ability and continuum of severity. Their behaviours present a barrier to learning and persist despite the implementation of an effective school behaviour policy and personal/social curriculum. They may be withdrawn or isolated, disruptive and disturbing, hyperactive and lack concentration, have immature social skills or present challenging behaviours.”\(^{42}\) Children and young people with BESD can be either demonstrative or withdrawn and uncommunicative, and can have a range of difficulties such as: emotional disorders; eating disorders; conduct disorders such as oppositional defiance disorder (ODD); hyperkinetic disorders including attention deficit disorder (ADD) or attention deficit hyperactivity disorder (ADHD); and syndromes such as Tourette’s. Children and young people should be recorded as BESD if additional educational arrangements are being made to support them.

2.3.4 Hearing impairment

For educational purposes, pupils are regarded as having a hearing impairment if they require hearing aids, adaptations to their environment and/or particular teaching strategies in order to access the concepts and language of the curriculum.\(^{31}\) The National Service Framework for Children\(^{43}\) estimates that prevalence of permanent hearing loss is nearly two per 1,000 children at age 9-16 years, and one out of every 1,000 babies are born with permanent deafness or hearing impairment that significantly affects their language and social development. A further one per 1,000 have a deafness with some effect on language and social development.

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\(^{36}\) National Institute for Health and Clinical Excellence (Sept 2011) Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum NICE clinical guideline 128 guidance.nice.org.uk/cg128

\(^{37}\) Department for Education (July 2013) Special Educational Needs in England January 2013: Statistical first release


\(^{42}\) Department for Education and Skills (2005) Data Collection by Type of Special Educational Need


2.3.5 Visual impairment

Visual Impairment can include a range of difficulties from partial sight to blindness.\textsuperscript{44} Research shows that while there are studies estimating prevalence of visual impairment in the older population there is very little data on younger age groups in the UK, including younger adults.\textsuperscript{45} Local Authority service data tends to show prevalence of visual impairment at approximately 20 per 10,000 children, yet the prevalence rate reported by the Department of Education (DfE) based on pupil level data is 10.5 per 10,000. This difference could be accounted for as the DfE estimate only includes children whose primary need is visual or multi-sensory impairment.

2.3.6 Multi-sensory impairment

Children with multi-sensory impairment have a combination of visual and hearing difficulties and many also have additional disabilities. Children and young people are only recorded as multi-sensory impaired if their sensory impairment is their greatest need and as such, the complex needs of those with multi-sensory impairment makes it difficult to ascertain intellectual ability.\textsuperscript{31}

2.3.7 Learning disability and learning difficulties

A learning disability affects the way a person understands information and how they communicate, meaning they may have difficulty: understanding new or complex information; learning new skills and coping independently. Learning disability is a lifelong condition evident from childhood and encompassing a range of conditions and levels of severity which may be accompanied by physical, psychological and psychiatric illness and disability. Associated impact on an individual’s educational, social, economic and life choices, with difficulties with social communication (linked to increased challenging behaviour) are central to the reduction of access to education, employment and social integration.\textsuperscript{46} There are four recognised types of learning difficulty:

- **Specific learning difficulty (SpLD):** Specific Learning difficulties is an umbrella term for all those displaying difficulties across their learning, whether it is reading, writing, spelling, or numeracy, so that their performance in these areas is below that of other areas. Pupils may also have problems with short-term memory, organisation and co-ordination and the range of severity of their impairment varies greatly. Specific Learning Difficulties include: Dyslexia; dyscalculia and dyspraxia.\textsuperscript{47}

- **Moderate learning difficulty (MLD):** Attainment for those with MLD will be below expected levels in all or most areas of the curriculum, despite appropriate interventions. Those with MLD may also have associated speech and language delay, low self esteem, poor concentration and under-developed social skills.\textsuperscript{37}

- **Severe learning difficulty (SLD):** Children and young people with SLD have significant intellectual or cognitive impairments which have a major effect on ability to participate in the curriculum without support in all areas. There may also be associated difficulties with mobility, co-ordination, communication and self help skills.\textsuperscript{37}

- **Profound and multiple learning difficulty (PMLD):** A child has PMLD when they have more than one disability, with the most significant being a learning disability.\textsuperscript{48} These young people have severe and complex learning needs and require a high level of adult support for both learning and personal needs. Communication is mostly by gestures, eye-pointing, symbols or simple language.\textsuperscript{37}

It is estimated that in the UK approximately 20 in 1,000 people have mild to moderate learning disability and 3–4 in 1,000 people have severe or profound Learning disability.\textsuperscript{49} It can be estimated that there are about 210,000 people with severe LD in England (around 25% of whom are under 16 years of age), and about 1.2 million people with mild to moderate LD. Evidence from QOF registers in England in 2012/13 suggest that primary care will have reported lower numbers than predicted, with only around 5% of all those aged 18 years and over with any form of learning disability being on a

\textsuperscript{44} Department for Education and Skills (2005) Data Collection by Type of Special Educational Need
\textsuperscript{47} Department for Education and Skills (2005) Data Collection by Type of Special Educational Need
\textsuperscript{49} Department of Health (2009) Valuing People Now: a new three-year strategy for people with learning disabilities ‘Making it happen for everyone’
2.3.8 Downs syndrome

Downs Syndrome is a chromosomal disorder caused by the presence of an additional chromosome and is the most frequent genetic cause of mild to moderate intellectual and developmental disabilities, occurring in approximately one in every 800 live births. The incidence of Downs Syndrome rises with maternal age from one in 1,000 for those aged under 30 years, one in 400 for those aged over 35 to one in 60 by the age of 42 years. Hearing loss, congenital heart disease and vision disorders are more prevalent amongst those with Downs Syndrome as well as seizure disorders such as epilepsy (National Institute of Health, 2010). In 2005, the prevalence of live and still born babies in England with Down’s syndrome was 6.6 per 10,000 live births, however prevalence estimates by the British Isles Network of Congenital Anomaly Registers shows that the prevalence for Downs Syndrome nationally appears to have decrease by, on average, 1% between 2006 and 2010. There are regional variations in prenatal diagnosis of Downs Syndrome, possibly due to differences in screening tests offered, uptake of tests and wider social factors. In 2010 the South East region had the second highest percentage of cases of prenatally diagnosed Downs Syndrome (74%) in the country behind London.

2.3.9 Speech, language and communication needs

Children and young People with speech, language and communication needs have difficulties in understanding and/or making others understand through spoken language, and their speech and language skills may be significantly behind their peers and may be poor or unintelligible. The Bercow review of services for children and young people with SLCN suggests that there is insufficient understanding amongst policy makers, commissioners and sometimes families and carers about the centrality of speech, language and communication as an essential life skill for social, emotional and educational development. Based on School Census Data it has been estimated that around 0.4% of children in the UK aged 5-16 years have speech and language impairments as a primary need. The Royal College of Speech and Language Therapists (RCSLT) estimate that 50-90% of the learning disabled population have communication difficulties and one third of all Speech and Language therapy (SALT) services in the UK are directed at the learning disabled population.

2.3.10 Congenital anomalies

In 2010, the perinatal mortality rate in England and Wales was 74 per 10,000 total births, of which an estimated 16% (12 per 10,000 total births) had a congenital anomaly. Latest national data (released September 2013) indicates that the rate of central nervous system anomalies per 10,000 births declined nationally from 11.4 in 2008 to 11.1 in 2010, yet in the South East the rate has increased over the same time period from 7 to 9.9.

2.4 Health needs

People with disabilities are particularly vulnerable to any deficiencies in health care and may experience greater vulnerability to secondary conditions such as pressure ulcers and pain, co-morbid conditions, age-related conditions, for example some people with developmental disabilities show signs of premature ageing in their 40s, engaging in risk behaviours such as poor diet and smoking, and higher rates of premature death, particularly for those with intellectual impairments. Barriers to health care can include affordability of health services and transportation, lack of appropriate services, physical barriers such as inadequate bathroom facilities, and inadequate skills and knowledge of health workers.

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50 Health & Social Care Information Centre (October 2013) Disease Prevalence: Quality and Outcomes Framework (QOF) for April 2012 - March 2013, England
56 World Health Organisation (2012) Factsheet no 352 Disability and Health
2.4.1 Mental health
Children with long term physical conditions are more likely to have higher rates of mental health problems⁵⁷, and people with learning disabilities have an increased risk of developing psychological problems.⁵⁸ Mental health issues are more prevalent in those with SEN than those without, and levels of mental health problems increase with levels of educational support needed.⁵⁹ Mental health issues exhibited most frequently in children with SEN including conduct disorder, depression and suicide, ADHD, obsessive compulsive disorder and schizophrenia.⁶⁰ Research suggests that children with a learning disability are over twice as likely to experience anxiety disorders and approximately six times as likely to experience conduct disorders⁶¹, yet The Prime Ministers Strategy Unit found that mental health services for children with learning disabilities are often under-resourced within Child and Adolescent Mental Health Services (CAMHS).⁷³

2.4.2 Community nursing
Community Care Nurses enable care for children at home, reducing lengths of stay in hospital or residential care, and improving quality of life for families. It is also a more cost effective option. Community nurses care for the needs of: children with acute and short-term conditions; children with long-term conditions; children with disabilities and complex conditions; and children with life-limiting and life-threatening illness. Research shows that four out of five 12–14 year old severely disabled children need help with eating, washing, dressing and toileting. Children with complex needs are staying in hospital due to delays in funding and setting up care packages in the home. Parents report that, for example, home ventilation results in less time in hospital and feeling less tired,⁶² and research supports this by highlighting higher quality, more flexible coordinated nurse led home care can improve quality of life for children using ventilators.⁶³

Department of Health guidance⁶⁴ estimates that the national average cost of caring for a medically stable ventilator-dependent child in paediatric intensive care (PICU) is £750,000 per year; and for children requiring long term ventilation is £630,000 in PICU or £300,000 on a high dependency unit. This compares to caring for the same children in the community costing between £100,000 and £250,000 a year for a medically stable ventilator-dependent child,⁶⁵ and £160,000 for a child needing long term ventilation.⁶⁶

2.4.3 Palliative care
The estimated prevalence for children and young people likely to require palliative care services in England is 16 per 10,000 population aged 0-19 years,⁶⁷ which equates to 21,500 children and young people in 2011.⁶⁸

2.5 Wider determinants
There are many factors in addition to health status which can affect the quality of life of children and young people with disabilities, with research indicating a higher likelihood of discrimination, poor access to some health services and worse employment prospects as a result of a child’s disability, factors which all impact negatively on their health.⁶⁹

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⁵⁹ Meltzer H et al (2000) the mental health of children and adolescents in Great Britain
⁶¹ Emerson E and Hatton C. 2007. The Mental Health of Children and Adolescents with Learning Disabilities in Britain. Lancaster University
⁶² Royal College of Nursing and WellChild (2009) Better At Home campaign.
⁶⁴ Department of Health (2011) NHS at Home: Community Children’s Nursing Services March 2011
⁶⁷ International: Children’s Palliative Care Network (ICPCN) (accessed September 2013) The need for Children’s Palliative Care
http://www.icpcn.org.uk/page.asp?section=00010001000800002&sectionTitle=The+need+for+Children%27s+Palliative+Care
⁶⁸ ONS (accessed September 2013) Census 2011 Population estimates
2.5.1 Poverty
Research demonstrates a strong relationship between disability, low income and social exclusion and disability among families who have a disabled child. Approximately a third of children with SEN provision are eligible for free school meals (FSM), compared to just over 10% of pupils with no SEN eligible for FSM. Disabled children living in a household with one or more disabled parent or carer have an even greater risk of living in poverty, as do those in the 10% of families caring for more than one disabled child. Fewer than half families with a disabled child receive health-related or disability benefits. A survey by Carers UK found that half of all carers reported subsidising the costs of the disability of the person they care for because of inadequate disability benefits.

2.5.2 Social inclusion
National evidence shows families with disabled children feel excluded from social and recreational opportunities that other families enjoy, due both to physical accessibility and to other people’s attitudes. Children with learning disabilities in particular find it hard to socialise at school because they have difficulty understanding how to interact with their peers, and so they risk becoming isolated. Children with disabilities are likely to be living fairly solitary lives and to be largely dependent on families and parents for emotional support, yet a key identified need for children with disabilities is the desire for contact with others who have similar experiences. Such relationships can be a key information source for children with disabilities.

2.5.3 Looked after children
Children who have disabilities may be placed in residential care if families are unable to support them at home. Research suggests that while this cohort has a wide range of impairments, a “typical” child in residential care tend to be teenage boys with persistent development disorders such as autism, and at least one other disability. Disabled children living in residential care are more likely than those living at home to be vulnerable to abuse; feel isolated; not feel respected and be vulnerable to a lifetime of care. Evidence also suggests that there are particular needs around meeting the specialist dental needs of disabled looked after children and young people. Nearly 75% of the 28,500 children looked after for at least a year at the end of March 2011 had special educational needs, equating to a 3.5 times greater likelihood of SEN in looked after children (LAC) compared to all children. Current figures show that LAC children are also ten times more likely to have statements than all pupils, and LAC children with a statement have almost three times greater likelihood of having BESD than all pupils with statements.

2.5.4 Education
The vast majority of SEN pupils without a statement in 2011/12 attended state-funded primary (52%) or secondary schools (43%) with 4.5% attending independent schools. Overall this is a very similar pattern to all pupils, although pupils with SEN without a statement were much less likely to attend independent schools than all pupils. Pupils with SEN who had statements in 2011/12 were much more likely to attend maintained special schools (39%) (including general hospital schools and special

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71 Department of Education (2013) School Census an 2013 Figures
74 Department for Work and Pensions (July 2013) Fulfilling Potential: Building a deeper understanding of disability in the UK today
75 Carers UK (2007), Real change, not short change – time to deliver for carers, London: Carers UK
77 Department of Health (2012) Research and development work relating to assistive technology 2011-12
82 Department for Education (Oct 2012) Children with special educational needs: an analysis - 2012
academies), while 28% attended state-funded secondary schools, 26% state-funded primary schools, 5% independent schools and 2% non-maintained special schools.  

2.5.4.1 Educational attainment

Education is key to enabling an individual to fulfil their future potential, yet disabled young people face multiple barriers to achieving the outcomes their peers can expect. Children with SEN are only a third as likely to achieve national expectations as those without SEN. Pupils with visual impairments at School Action Plus or with a statement of SEN were most likely of all SEN types of need to achieve a good level of educational development, and pupils with severe learning difficulty or profound and multiple learning difficulties were the least likely to. Across all ages, levels of SEN provision, and subjects, pupils eligible for free school meals (FSM) are less likely to achieve expected levels of development than those not eligible. The percentage of pupils achieving at least five GCSEs at grades A* to C or by the age of 19 years is lower for pupils with SEN than for those with no identified SEN, as is the percentage of 19 year olds achieving 2 or more A-levels or equivalent. There are several factors contributing to lower attainment levels for children with SEN:

- inconsistent approaches to identification;
- assumptions and low aspirations;
- differing levels of confidence and skills of professionals;
- low prior attainment at Early Years Foundation Stages or Key Stages;
- low levels of and support for parental engagement;
- related poorer wellbeing such as bullying or exclusion;
- lower accessibility to qualifications

2.5.4.2 School absence and exclusions

The latest national data indicates that the overall absence rate decreased from 5.8% in 2010/11 to 5.1% in 2011/12, continuing a downward trend. However, absence levels are substantially higher for pupils with SEN compared to those with no SEN and the gap has changed little over recent years. Pupils with a statement have the highest rate of overall absence (1.8 times pupils with no identified SEN) and are over three times more likely to be persistent absentees.

Pupils with profound and multiple learning disabilities (PMLD) and behavioural, emotional and social difficulties (BESD) are also most likely to be persistently absent. Children and young people with PMLD have the highest levels of overall and authorised absence of all primary types of need, and pupils with BESD are almost twice as likely as any other type of need to have unauthorised absence.

In general, girls are more likely to be persistent absentees than boys, while boys are more likely to be excluded than girls regardless of level of SEN provision. Pupils with SAP are over three times more likely to receive a fixed period exclusion, and over five times more likely to be permanently excluded than those with no SEN. Compared to those with no SEN, pupils with SEN are less likely to receive a fixed period exclusion due to bullying, theft, drugs and alcohol, or physical assaults on pupils, yet more likely to receive a fixed period exclusion due to physical assaults on and verbal abuse against adults and persistent disruptive behaviour. The most common reasons for permanent exclusions for SEN pupils in 2010/11 were persistent disruptive behaviour and physical assault against a pupil.

84 Department for Children, Schools and Families (2010) Breaking the link between special educational needs and low attainment Everyone’s business.
87 Department for Education (March 2013) Statistical First Release pupil absence in schools in England, including pupil characteristics: 2011/12
2.5.5 Not in education, employment or training (NEET)
Nationally it is estimated that disabled young people are twice as likely as others to be NEET and it is estimated 61,700 young people aged 18 to 24 who had a statement of SEN will be NEET in 2014/15. In 2010/11, 59% of disabled graduates were in employment and 15% were assumed to be unemployed, compared to 65% and 11% of non-disabled graduates. In the same period, 16% of disabled graduates were in further study compared to 15% of non-disabled graduates. The figures for disabled graduates have not significantly changed since 2004/05.

2.5.6 Further education
Young disabled students not in receipt of Disabled Students Allowance (DSA) (9%) are more likely than young disabled students in receipt of DSA (5.5%) and non-disabled students (7%) to drop out of higher education after the first year. This is mirrored for mature disabled students. Figures from 2010/11 show that disabled students who completed their first degree were less likely to attain a first class or upper second degree than non disabled people. In 2010/11, 60% of disabled students attained a first class or upper second class degree when completing their first degree in comparison to 64% of non disabled students.

2.5.7 Transition
Children are surviving longer with conditions they would previously have died from in childhood and so support with the transition from children to adult services is becoming a more prevalent issue. Transition services have been developed to support young people and their families through the transition into adulthood to ensure that disabled young people have the same rights and opportunities as all young people. Health-related quality of life for young people with complex health needs and disabilities can be improved by a good transition, and a well-planned transition improves health, education and social outcomes for young people. A poor transition out of children’s services without continuity of care can lead to disengagement with services and can have serious outcomes for young people. This time of transition is described as a “cliff edge” for young people and their families who feel unprepared for the process and have anxiety about whether the services will fall away when the child becomes 16. The transition from child to adult services is further complicated by the differing ages at which young people move from one service to the other. For example, a disabled young person may move from paediatric to adult health services at the age of 16, but from children’s to adult social care at 18, and this is alongside transitions in their education which means disabled young people may historically be going through several transition processes at once. National evidence shows that young people with a diagnosis of autism but with no learning difficulties (that is, those with ‘high functioning autism’ (HFA) or Asperger’s syndrome (AS)) whilst not eligible for support from adult social care, do have significant support needs to enable them to successfully transition into adulthood and parents can often find themselves, often reluctantly assuming a keyworker role.

2.5.8 Employment
It has been estimated that, of those known to services in England, 28% of people with mild/moderate learning disabilities and 10% of people with severe learning disabilities are in paid employment. Less than two thirds of employers are prepared to employ a person with a physical disability, with

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95 Department for Education (March 2013) Evidence Pack Special Educational Needs: Children and Families Bill 2013
96 Higher Education Statistics Agency (February 2013) Destinations of Leavers from Higher Education Survey (DLHE)
98 Higher Education Statistics Agency (July 2012) Life Opportunities Survey
94 National Transition Support Team Information Sheet: The Transition Support Programme: Improving support for disabled young people in transition to adulthood
95 Department for Children, Schools and Families (2008) Transition: moving on well. A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability.
96 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.
97 University of York (2013) Transition to adult services and adulthood for young people with autistic spectrum conditions SPRU
only one third willing to employ a person with mental health issues.\textsuperscript{99} According to the Department of Health, unemployment rates for both young disabled people and young non-disabled people are falling, yet, while there are now more disabled apprentices, disabled young people are still under-represented. In comparison to older disabled workers, young people are five times more likely to report having been refused a job or interview because of their disability.\textsuperscript{100}

2.5.9 Housing
Children living in poor housing conditions are more likely to: have mental health problems; contract meningitis; have respiratory problems; experience long-term ill health and disability; experience slow physical growth and have delayed cognitive development.\textsuperscript{101} Disabled children experience greater disadvantage than most, even in comparison to other groups of disabled people. 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. Families of children with disabilities have a 50% higher chance of living in overcrowded accommodation and face multiple housing difficulties, including lack of space: either for play; for privacy; for storing equipment or for carrying out therapies, while others included access and housing condition problems.\textsuperscript{102}

2.5.10 Equipment and environment
There are up to 6,000 children in Great Britain living at home who are dependent on assistive technology and one third of parents with a severely disabled child under the age of two uses in excess of three pieces of equipment daily to provide basic care.\textsuperscript{103} Over the last decade the number of technologically dependent children being cared for at home has increased significantly, reflecting both improving technology, and increasing clinical expertise. However this increase will need to be supported through the transition into adult services in the near future and research suggests that few specific services currently exist to do this.\textsuperscript{104}

2.5.11 Respite Care
Respite care offers opportunities to a disabled child that would not otherwise be available, in terms of a therapeutic opportunity which promotes independence and quality time which is beneficial for both the young person and their family.\textsuperscript{105} However, a review of children’s services suggests current level of demand for short break services is high and there is difficulty meeting this demand.\textsuperscript{106}

2.5.12 Childcare
Childcare that is appropriate for disabled children is scarce and expensive and varies significantly according to the disability of the child. National research acknowledges that parents and carers of children who have a disability or special needs are poorly served by the current system of childcare.\textsuperscript{107} In England in 2008, children with special educational needs were less likely to receive formal childcare (37%) than those without special educational needs (45%).\textsuperscript{108,109} A 2012/13 childcare cost survey reported that only 14% of local authorities felt they had sufficient childcare for disabled children.

\textsuperscript{100} Department for Work and Pensions (July 2013) Fulfilling Potential: Building a deeper understanding of disability in the UK today
\textsuperscript{102} Every Disabled Child Matters (2008) Disabled children and housing
\textsuperscript{104} Wallis et al (2010) Children on long-term ventilatory support: 10 years of progress
\textsuperscript{107} Family and Parenting Institute (2013) Childcare Costs Survey 2013
\textsuperscript{109} Daycare Trust (2010 a) Childcare costs survey 2010, London: Daycare Trust
The need for childcare for families with disabled children revolves around three key principles: accessing childcare in order: to work; to meet other family commitments; to meet the disabled child’s needs for social activities, inclusion, interaction and friendship. Of those needing childcare in order to work, frequently cited difficulties include:

- Refusal of group childcare providers to accept their child unless 1-1 support was in place;
- Prohibitive cost of 1-1 support in group childcare settings;
- Lack of availability of private childminders (especially in rural areas);
- Additional costs charged by private childminders for disabled children;
- Difficulties in finding childminders who would accept their children for reasons relating to either the child’s impairment, behaviour or support needs.\(^{110}\)

2.5.13 Transport

Transport is a key issue in terms of accessing services including getting to and from school or nursery and accessing after school clubs and leisure activities. Transport is frequently identified as the largest barrier to accessing extended provision, with research showing that 10% of disabled young people believe transport to be the main barrier to participation in sports events.\(^{111}\) 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.

2.5.14 Lifestyle factors

2.5.14.1 Substance misuse

The extent of drug and alcohol use by young people is difficult to assess due to the illegal and hidden nature of the activity. National research suggests that by 18 years of age about a third of young people will have experimented with illegal drugs and 90-95% of young people will have tried alcohol. Evidence 2008/09 suggests that pupils with learning difficulties are significantly more likely to take an illicit substance than those without (14% compared to 11% in 2008/09).\(^{112}\)

2.5.14.2 Obesity

Being obese or overweight can have a severe impact on health, increasing the risk of type 2 diabetes, heart and liver disease and some cancers, and it is estimated to cost the NHS £4.2 billion per year.\(^{113}\) Analysis of the Health Survey for England found that children who have a limiting illness are more likely to be obese or overweight, particularly those who also have a learning disability. Those with a learning disability and a limiting illness are one and a half times more likely to be overweight or obese than those without a limiting illness or a learning disability. The likelihood of being obese increases with age, and boys with a limiting illness are more likely to be obese or overweight than girls.\(^{114}\)

2.5.14.3 Sport and leisure

Research suggests that play and leisure are a priority for disabled children as opportunities to express choices, develop independence, learn new skills and develop social relationships.\(^{115}\) However, young people with a disability are more likely to be inactive (60%) than those who do not have a disability (47%).\(^{116}\) Evidence suggests that disabled children are as likely as other children to visit a library or museum at least once a year, but less likely to take part in sport.\(^{117}\) The annual active people survey for those aged 16 years and over found sports participation to be significantly lower amongst people with disabilities than non-disabled people across all ages: disabled people aged 16 to 19 were 4% less likely to exercise at least three times a week, and those aged 20 to 24 were 8% less likely. However, weekly participation in sport has seen a significant increase among disabled people compared with a

\(^{110}\) Department for Education (2011) Disabled Children’s Access to Childcare (DCATCH): a qualitative evaluation


\(^{112}\) Department for Children, Schools and Families (October 2009) Children with special educational needs 2009: an analysis.


\(^{114}\) Chimat (2011) Disability and obesity: the prevalence of obesity in disabled children


significant decrease in the general population. Participation for those with disabilities across all ages is highest in swimming, although participation has reduced in recent years.\textsuperscript{118} Swimming has also been found to be the most frequent activity undertaken by children and young people with disabilities or severe illnesses within school hours, with disabled young people more likely to take part in swimming in school compared to the general population of young people. Disabled children, however, have considerably lower levels of out of school sporting activity compared to non-disabled children, with the main reasons for this cited as: lack of money, health condition, and unsuitable sporting facilities.\textsuperscript{119}

\section*{2.6 Families and carers}

There are an estimated 6 million carers of adults and children in the UK, a significant number of whom are parent carers. This population saves the economy an estimated £87 billion a year through unpaid support.\textsuperscript{120} People with high levels of caring responsibility are twice as likely to suffer from poor health as those without caring responsibilities, and are more likely to experience a relationship breakdown.\textsuperscript{121} Caring for a child with disabilities is a complex role that does not stop when a child reaches adulthood, with an estimated 60\% of adults with learning disabilities living with their families.\textsuperscript{122} National evidence suggests that with the right planning and support through transition, more adults with autism would live independently.\textsuperscript{123}

In the 2011 Census, there were 178,000 young carers (aged 5 to 17 years) in England and Wales, an increase of nearly 19\% from the 150,000 carers in 2001. This increase has been observed across all regions, and the South East has seen the biggest rise (41\%), over twice the national average (19\%). It also has the lowest proportion of the population who are unpaid carers in the country (2\% compared to a national average of 21\%). Over half of all young carers are girls (56\%). The majority (80\%) of young carers contribute 1 to 19 hours of unpaid care per week (in line with other age groups); while 9\% provide 50 or more hours.\textsuperscript{124} A lack of professional awareness and reluctance of families to engage with services are key barriers to identifying young carers.\textsuperscript{125} In one study, over 80\% (46 parents) of parents of a child with disabilities reported their non-disabled child had a caring role for their sibling.\textsuperscript{126}

\begin{appendix}
\section*{Appendix A}

Appendix A outlines national evidence of effectiveness and best practice with regards to addressing the needs of children and young people with special educational needs and/or disabilities in the UK and is available on request.
\end{appendix}

\begin{thebibliography}{9}
\bibitem{118} English Federation of Disability Sport (2012) Overall participation of disabled people in sport. Active People Survey 5 (2010-11)
\bibitem{122} MIND Website (Accessed 2013) Learning disabilities and mental health problems Factsheet.
\bibitem{124} Office of National Statistics (June 2013) A summary of unpaid care by 5 to 17-year-olds in England and Wales.
\end{thebibliography}
### 2.7 SUMMARY OF KEY NATIONAL FINDINGS

<table>
<thead>
<tr>
<th>Area</th>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>SEND REFORMS</td>
<td>National legislative reforms to special educational needs and disability provision represent the greatest ever change to service provision and will:</td>
</tr>
<tr>
<td></td>
<td>o extend the SEN system from birth to 25;</td>
</tr>
<tr>
<td></td>
<td>o give children, young people and their parent’s greater control and choice in decisions;</td>
</tr>
<tr>
<td></td>
<td>o make things simpler and more joined up.</td>
</tr>
<tr>
<td>Health</td>
<td>- Children with certain conditions are surviving longer</td>
</tr>
<tr>
<td></td>
<td>- Children with learning disabilities have a greater likelihood of psychological health problems</td>
</tr>
<tr>
<td></td>
<td>- Children with disabilities are more likely to have poor access to some health services</td>
</tr>
<tr>
<td>Deprivation</td>
<td>- 29% of children who have a disability are estimated to live on/near the margins of poverty.</td>
</tr>
<tr>
<td>Social Exclusion</td>
<td>- Children with disabilities are more likely to experience social exclusion, discrimination and bullying</td>
</tr>
<tr>
<td>Education</td>
<td>- 20% of school aged children are identified as having Special Educational Needs</td>
</tr>
<tr>
<td></td>
<td>- Children with special educational needs are 3 times more likely to be persistent absentees</td>
</tr>
<tr>
<td>Mental Health</td>
<td>- Children with special educational needs or disabilities are more likely to have a mental health issue.</td>
</tr>
<tr>
<td>Employment</td>
<td>- Disabled young people aged &lt;25 are twice as likely to be NEET</td>
</tr>
<tr>
<td>Housing</td>
<td>- Children with disabilities have a 50% higher chance of living in overcrowded accommodation</td>
</tr>
<tr>
<td></td>
<td>- Disabled children needing housing adaptations are least likely to be living in suitable housing in</td>
</tr>
<tr>
<td></td>
<td>- comparison to other age groups of disabled people.</td>
</tr>
<tr>
<td>Wider Implications</td>
<td>- The unpaid carer population saves the UK an estimated £87 billion a year.</td>
</tr>
<tr>
<td></td>
<td>- People with high levels of caring responsibility are twice as likely to suffer from poor</td>
</tr>
</tbody>
</table>
East Sussex County consists of two boroughs (Eastbourne and Hastings) and three districts (Lewes, Rother and Wealden). Wealden is the largest district/borough (144,000 persons) and Hastings is the smallest (87,500 persons). There are 3 Clinical Commissioning Groups (CCGs) in East Sussex: High Weald Lewes Havens CCG; Eastbourne, Hailsham and Seaford CCG; Hastings and Rother CCG (Figure 3). From an NHS perspective, Eastbourne, Hailsham and Seaford is the largest CCG in East Sussex (184,000 patients) and High Weald Lewes Havens CCG is the smallest (164,000 patients).

3.1 Local population

According to the latest 2012 data from the Office for National Statistics (ONS) the resident population of East Sussex rose from 497,000 people in 2002 to 531,000 in 2012 (an increase of 6.9%) (Figure 4).

---

127 East Sussex County Council Public Health Intelligence Team (February 2013) Commentary for East Sussex based on JSNA Scorecards, January 2013

Source, ONS: 2013
The 2012 ONS estimates showed that East Sussex has 27% of the population aged 25 years or under. This is considerably less than the South East (30%) and England (31%)\textsuperscript{128} showing that East Sussex has a much older population than both nationally and regionally. Figure 5 shows the East Sussex population by five year age bands for children and young people in the county.

![Figure 5: 2012 population of children and young people aged 0-24 in East Sussex by area](image)

In East Sussex the 10-15 year age band is the largest group of children and young people among 0 to 24 year olds. Hastings has the largest percentage of the 0 to 24 year old population Rother the smallest. In comparison to 2008 estimates, the overall 0 to 24 year old population in East Sussex has decreased slightly. This is in line with the national picture, although regionally the population of children and young people has remained stable over the last 5 years. Compared to 2008 figures in East Sussex, there is a slight increase of 0.2% in the 0 to 4 years and 20 to 24 years populations, a slight decrease of 0.2% in the 16 to 19 years population, while the 10 to 15 years population has decreased by 0.5%.\textsuperscript{129}

### 3.1.1 Poverty

Income Deprivation Affecting Children Index (IDACI) data captures the proportion of the population experiencing income deprivation in an area and represents children aged 0 to 15 living in income deprived households in each Lower Layer Super Output Area (LSOA) (approximately 1,500 households). Hastings has the highest IDACI score in East Sussex (29.6) indicating that it is the most income deprived area for children in the county, followed by Eastbourne (22.3), Rother (18), Lewes (14.5) and Wealden (10.4).\textsuperscript{130} Within these areas, income deprivation varies greatly by locality, from 46% in Central St Leonards, to 3% in Crowborough St Johns.\textsuperscript{131} Of the 326 Local and unitary authorities in England in 2010, Hastings ranked 40\textsuperscript{th} most deprived, Eastbourne 99\textsuperscript{th}, Rother 149\textsuperscript{th}, Lewes 199\textsuperscript{th}, and Wealden 274\textsuperscript{th}.\textsuperscript{132} These rankings are reflected in those of the local clinical commissioning groups.

\textsuperscript{128} ONS, (2013) 2012 Mid Year Estimates

\textsuperscript{129} ONS, (2013) 2012 Mid Year Estimates


\textsuperscript{131} East Sussex Public Health Intelligence Team (Jan 2013) Indicator scorecards: LA view.

\textsuperscript{132} Association of Public Health Observatories (Mar 2011) Child poverty - IMD 2010 IDACI
3.1.2 Prevalence

The Thomas Coram Research Unit (TCRU) estimates that the mean percentage of disabled children in English local authorities is between 3.0% and 5.4%. If applied to East Sussex in 2012 this would equate to between 3,500 and 6,300 0-19 year olds experiencing some form of disability, or between 4,300 and 7,700 0 to 24 year olds in the County. However, these numbers are still potentially an underestimate as not all children with disabilities or complex health needs are registered on DLA or SEN.

Current estimates suggest that nationally 1.7 million, (one in five pupils) have SEN. In East Sussex this would equate to about 14,000 children aged 5 to 16 having at least one special educational need. In 2012 there were 13,900 pupils with SEN provision in East Sussex which fits with national estimates. A total of 410 children received statements of special educational needs for the first time during the 2012 calendar year, nearly a quarter of which (102) were issued to children under the age of 5 years, over half (227) to children aged between 5 and 10 years, and just under a fifth to 11 to 15 year olds.133

3.1.3 Disability living allowance

Between February 2010 and February 2013 the number of DLA claimants aged under 16 in East Sussex has steadily risen from 2,700 to 2,840 (Figure 6), an increase of just under 5%. This is despite a decreasing under 25 population in the county over the last 5 years which suggests, as is the case nationally, the number of young people with disabilities and long term illnesses is increasing in East Sussex.

**Figure 6: Disability living allowance (DLA) claimants aged under 16 in East Sussex, 2010-2013**

Although the level of increase at county level is below that of the regional (+8.5%) and national (+8%) figures there is variation at district and borough level. The greatest increase in under 16 year old claimants of DLA has been in Eastbourne (+12%) and Lewes (+10.6%), and Wealden (+8%), while Rother has seen no change in claimants over the past 5 years, and claimants in Hastings have decreased by 4.5% (Figure 7). The number of boys in the county claiming DLA has increased by 4%, compared to an increase of 7% for girls, although there are still 2 ½ times as many boys (2,000) as girls (840) aged under 16 years claiming DLA.

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133 East Sussex SEN team (2013) Department for Education Form SEN2 2013
The 2009 East Sussex needs assessment for children with complex needs\textsuperscript{134} used information held on GP registers to estimate the numbers of 0 to 20 year olds with specific conditions across the county (table 4). However, details of the age breakdown of patients in the GP practices who did not submit data are not specified. County level estimates use the median rate of those who submitted data (and as such should be treated with caution).

Table 4: Children on GP registers with specific conditions relating to complex health needs in East Sussex

<table>
<thead>
<tr>
<th>Condition</th>
<th>Numbers recorded at 47 practices</th>
<th>Rate of recorded children per 1,000</th>
<th>Estimated numbers for East Sussex</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cerebral Palsy</td>
<td>116</td>
<td>1.5</td>
<td>182</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>23</td>
<td>0.3</td>
<td>36</td>
</tr>
<tr>
<td>Downs Syndrome</td>
<td>78</td>
<td>1.0</td>
<td>123</td>
</tr>
<tr>
<td>Hearing Impairment</td>
<td>1,611</td>
<td>21.3</td>
<td>2,530</td>
</tr>
<tr>
<td>Attention Deficit Disorder</td>
<td>680</td>
<td>9.0</td>
<td>1,068</td>
</tr>
<tr>
<td>Autism</td>
<td>639</td>
<td>8.4</td>
<td>1,004</td>
</tr>
<tr>
<td>Learning Disability</td>
<td>295</td>
<td>3.9</td>
<td>463</td>
</tr>
<tr>
<td>Visual Impairment</td>
<td>57</td>
<td>0.8</td>
<td>90</td>
</tr>
</tbody>
</table>

Source: Options UK, 2009

3.2 Type of special educational need and disability

3.2.1 Downs syndrome

National evidence indicates that the South of England prevalence rate for Downs Syndrome is 2.6 per 1,000, similar to national prevalence. Therefore prevalence from GP registers is lower than expected for East Sussex.

3.2.2 Autistic spectrum disorder

The British Association for Child and Community Health (BACCH) has created a calculator of expected service demands for certain clinical conditions including ASD based on a local areas child population and birth rate.\textsuperscript{135} According to the calculator, the prevalence of ASD amongst children in the UK is

\textsuperscript{134} Options UK (2009) Needs Assessment for Children with Diabetes, Epilepsy and Complex Health Needs
\textsuperscript{135} http://www.bacch.org.uk/publications/other_service_improvement.php
1.57%\(^{136}\) (including previously undiagnosed cases). In total within the 0-19 year population of East Sussex we would expect approximately 1,840 children and young people to have Autism Spectrum Disorder, with an incidence (expected new cases) of 80 per year. The tool also calculates that there would be 240 expected appointments with community child health services for ASD each year.

Using 2014 mid-year population estimates and registered births in East Sussex (which includes calculations for children moving into and out of the county), Table 5 shows the estimated prevalence and incidence of ASD in East Sussex with the greatest expected incidence in Wealden based on 0-19 population size. Estimates of future prevalence have been calculated using the latest East Sussex County Council (ESCC) (dwelling-led) population projections, and CCG projections. CCG projections suggest a slightly higher total prevalence for East Sussex than ESCC projections because the former is based on ward level data aggregated into CCG area, while the latter is based on district level data. These figures are only a broad estimate of the prevalence and incidence of ASD, and they indicate a projected fall in actual numbers of 0-19 year olds with ASD over the next five years.

<table>
<thead>
<tr>
<th></th>
<th>Estimated Prevalence of ASD (1.57%)</th>
<th>Estimated incidence of ASD (new cases per year)</th>
<th>Expected community child health appointments per year</th>
<th>Estimated future prevalence in 2021</th>
</tr>
</thead>
<tbody>
<tr>
<td>East Sussex</td>
<td>1,840</td>
<td>80</td>
<td>240</td>
<td>1,785</td>
</tr>
<tr>
<td>Eastbourne</td>
<td>350</td>
<td>15</td>
<td>50</td>
<td>335</td>
</tr>
<tr>
<td>Hastings</td>
<td>340</td>
<td>15</td>
<td>50</td>
<td>325</td>
</tr>
<tr>
<td>Lewes</td>
<td>340</td>
<td>15</td>
<td>40</td>
<td>340</td>
</tr>
<tr>
<td>Rother</td>
<td>280</td>
<td>10</td>
<td>35</td>
<td>265</td>
</tr>
<tr>
<td>Wealden</td>
<td>530</td>
<td>20</td>
<td>65</td>
<td>525</td>
</tr>
<tr>
<td>EHS CCG</td>
<td>615</td>
<td>30</td>
<td>90</td>
<td>620</td>
</tr>
<tr>
<td>H&amp;R CCG</td>
<td>620</td>
<td>30</td>
<td>85</td>
<td>615</td>
</tr>
<tr>
<td>HWLH CCG</td>
<td>610</td>
<td>25</td>
<td>70</td>
<td>580</td>
</tr>
</tbody>
</table>


It is estimated that between 40% and 67% of autistic children may have a learning disability\(^{137,138}\) equating to between approximately 740 and 1,230 children and young people in East Sussex with autism who have a learning disability. However, the National Autistic Society states that it’s not possible give an accurate estimate because some very able people with ASD may never come to the attention of services as having special needs because they have learned strategies to overcome any difficulties with communication and social interaction, while others may be able intellectually, but need support because the degree of social interaction impairment hampers their chances of achieving independence.\(^{139}\) It is also estimated that approximately a third of children with a learning disability also have autism.\(^{140}\) Estimated prevalence for learning disability is 2.6% of pupils\(^{141}\) which equates to 1,680\(^{142}\) 5-19 year olds with a learning disability in East Sussex, approximately 570 of whom may have autism.

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\(^{142}\) Based on 2016 numbers of school pupils in East Sussex, provided by Data Research and Information Team, Children’s Services, ESCC
The rate of Autistic Spectrum Disorder in East Sussex was consistently above national and regional rates until 2011 but over the last three years has been statistically similar to both nationally and regionally (Table 6). In 2014 the ASD rate for children in 2012 children in East Sussex was 11.3 per 1,000 pupils known to schools. This identifies how many children with autism have been recognised, diagnosed and recorded as having ASD by schools.

Table 6: Children per 1,000 with ASD known to schools 2008-2014

<table>
<thead>
<tr>
<th>Year</th>
<th>England Average</th>
<th>South East</th>
<th>East Sussex</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008</td>
<td>5.84</td>
<td>6.70</td>
<td>7.62</td>
</tr>
<tr>
<td>2009</td>
<td>6.30</td>
<td>7.10</td>
<td>8.20</td>
</tr>
<tr>
<td>2010</td>
<td>6.90</td>
<td>7.90</td>
<td>9.30</td>
</tr>
<tr>
<td>2011</td>
<td>7.60</td>
<td>8.60</td>
<td>9.80</td>
</tr>
<tr>
<td>2012</td>
<td>8.17</td>
<td>9.30</td>
<td>9.84</td>
</tr>
<tr>
<td>2013</td>
<td>9.1</td>
<td>10.0</td>
<td>9.6</td>
</tr>
<tr>
<td>2014</td>
<td>10.8</td>
<td>11.7</td>
<td>11.3</td>
</tr>
</tbody>
</table>

Source: Public Health England August 2016

3.2.3 Learning difficulties
East Sussex has a significantly lower prevalence rate of moderate learning disabilities (14.9 per 1,000) and severe learning difficulties (2.7 per 1,000) than both England (19.7 and 3.7 respectively) and the South East (16.5 and 3.2 respectively). However, the rate of moderate learning difficulties (MLD) in East Sussex has been growing significantly faster (+0.45 per 1,000) than for England (+0.05 per 1,000), while the rate for the South East region has decreased by -0.05 since 2008 (by -0.2 from 2011). This suggests that the rate of young people with MLD in East Sussex is rising out of proportion to both regional and national prevalence.

3.3 Health needs
Further information on some of the key issues outlined below can be found in the 2012/13 Annual Public Health Report: Reducing health inequalities among children and young people in East Sussex Director of Public Health Report 2012/13 http://www.eastsussexjsna.org.uk/publichealthreports

3.3.1 Maternal age
Maternal age is a pre-determinant of low birth weight and pre-term rates, with those at extreme ends of the maternal age spectrum having a higher prevalence of low birth weight or pre-term birth. In 2011/12 the birth rate for women aged 15 to 44 years in East Sussex was 66 per 1,000 women, with countywide variation from 71 per 1,000 in Hastings to 64 per 1,000 in Lewes. The rates of live births for women aged 15-19 years are highest in West Hastings and St Leonards areas. There are significantly higher live birth rates for younger mothers in Hastings, and these births correspond closely with areas of higher deprivation within the borough. High Weald, Lewes and Havens CCG has significantly lower recorded birth rates for mothers aged 15 to 34 years than for the County, but significantly higher rates for mothers aged 35 to 44.

3.3.2 Smoking at time of delivery and at 6-8 week check
Babies from areas of greater deprivation are more likely to be born to mothers who smoke, and to have much greater exposure to second-hand smoke in childhood. Smoking during pregnancy can cause a range of serious health problems, including lower birth weight, pre-term birth and placental complications which could lead to disabilities. In 2011/12, 16% of babies in the County were born to mothers known to be smoking at the time of delivery, with the same proportion of mothers still reporting they were smoking at 6-8 weeks. This compares to 13.2% of mothers known to be smoking at time of delivery nationally, and 12.9% in the South East. Percentages of mothers smoking at time of delivery are particularly high in the West Hastings area and significantly higher in Baird (39%).

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144 Public Health England (August 2013) Learning Disabilities Profile 2013: East Sussex
145 Public Health Intelligence Team (2013) JSNA Indicator Scorecards 2013
146 Health and Social Care Information Centre (13 June 2013) Statistics on Women’s Smoking Status at Time of Delivery: England
Bexhill Sidley (34%) and Hailsham East (52%). Of those registered by GP practice, smoking at delivery is significantly lower in Lewes and High Weald. 103

3.3.3 Low birth weight
Low birth weight reflects the health of mothers and babies and is associated with poor outcomes for babies including increased infant mortality. Good maternity and infant health care can make a significant difference, as can good social and family support. Low birth weight is more prevalent among lower socio-economic groups and varies widely according to socio-economic status. The main risk factors for the social gradient in low birth weight are nutritional status of the mother, smoking in pregnancy, substance misuse, low uptake of prenatal care and psycho-social factors causing stress and depression.147 Between 2009/10 and 2011/12, 7% of babies in East Sussex were of low birth weight (under 2,500 grams), compared to 6.5% in England.148 Birth weight does not vary significantly by District, Borough or CCG.149

3.3.4 Breastfeeding
In 2011/12 80% of mothers initiated breastfeeding, with a significantly higher percentage doing so in High Weald, Lewes and Havens CCG (85%) than the county as a whole, and a lower percentage in Hastings and Rother CCG (77%). This compares to a national average of 74%, and a regional average of 78%. Over the same time period, 49% of East Sussex mothers fully or partially breastfed at 6-8 weeks (of known breastfeeding status), compared to 47% in England. Once again, breastfeeding at 6-8 weeks was significantly higher in High Weald Lewes and Havens CCG and significantly lower than the county average in Hastings and Rother CCG, with particularly low rates in the Bexhill area. This is mirrored when looking at breastfeeding across districts and boroughs in the County.103

3.3.5 Palliative care
National research suggests that 16 out of every 10,000 children and young people aged 0 to 19 years are likely to receive palliative care. If this estimate is applied to the population of East Sussex there are currently 190 children and young people in the county likely to be receiving palliative care.

3.4 Wider determinants
3.4.1 Education
3.4.1.1 SEN provision in East Sussex
Between 2004 and 2010 SEN provision in East Sussex rose from 19% of the school population to 21%, with the greatest increase (2.7%) in those with School Action Plus, but no increase in those with statements. This represents a 4.4% increase in number from the 12,700 pupils with SEN in 2004 to the 13,500 pupils with SEN in 2013. Between 2010 and 2013 there was a 0.5% rise in statements locally (table 7). Nationally there has been a downward trend in statements since 2008.150

<table>
<thead>
<tr>
<th>Table 7: SEN provision in East Sussex January 2008 to January 2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008</td>
</tr>
<tr>
<td>No SEN</td>
</tr>
<tr>
<td>Statement</td>
</tr>
<tr>
<td>School Action Plus</td>
</tr>
<tr>
<td>Statement or SAP</td>
</tr>
<tr>
<td>School Action</td>
</tr>
<tr>
<td>Statement, SAP or SA</td>
</tr>
<tr>
<td>Total school population</td>
</tr>
</tbody>
</table>

148 HES online (accessed September 2013) Table 28: Singleton and multiple deliveries* by birth weight and birth status, 2011-12
149 Public Health Intelligence (accessed August 2013) NHS Indicator Scorecards. East Sussex County Council
150 East Sussex County Council (2013) Children’s Services Portfolio Plan 2013/14 – 2015/16
Between 2004 and 2009/10 there was an upward trend in the numbers of children with special educational needs in both primary and secondary school, with the exception of those with statements in secondary school which remained relatively static as a percentage of the school population. Since 2010/11 there has been a decrease in those with school action or school action plus in both primary and secondary schools but there has been an increase in those with statements, particularly in primary schools (Figure 8 and Table 6).

**Figure 8: SEN provision in East Sussex in maintained primary and secondary schools 2004 to 2013**

SEN provision at school action level remains is for relatively similar numbers of pupils across all ages between 6 years and 14 years and falls by two thirds between ages 15 and 16. School Action Plus provision follows a similar pattern while provisions for children with statements increases with age until 15 years (Figure 9).

**Figure 9: SEN provision in East Sussex by age, 2013**

*numbers under 5 have been excluded

Speech, language and communication needs are most prevalent type of SEN in younger children aged between 2 and 10 years old, with proportion declining with age. The proportion of specific learning difficulties, severe learning difficulties, and behavioural emotional and social difficulties all increase with age (Figure 10). Autism Spectrum Disorder is most prevalent amongst those aged between 7 and 15 years old. The proportions of other types of SEN do not change significantly with age.

**Figure 10: Type of SEN by age, 2013**
There has been a continuing year on year upward trend of pupils with SEN provision for Autism Spectrum Disorder (ASD), visual impairments (VI), profound and multiple learning difficulties (PMLD) and Speech Language and Communication Needs (SLCN). The greatest decrease has been in the number of children with Severe Learning Difficulties (SLD) (Figure 11).

There appears to be a clear association between the distribution of pupils with SEN and the areas of the county within the most deprived LSOAs (Figure 12). Both IDACI and the SEN distribution indicate there are concentrations of children and young people with SEN in Hailsham, Newhaven and surrounding areas, Rother, Sidley, Polegate, Eastbourne and Battle. This correlation becomes less apparent when just looking at distribution of statements or SAP due to the lower numbers within each area.
Figure 12: Distribution of pupils with SEN (SA, SAP or Statement) – school census Jan 2013

*each LSOA is compared to the total population (percentage) of SEN children across East Sussex.

Source: School Census 2013, East Sussex County Council

Figure 13: Correlation between proportion of pupils with SEN and IDACI score.

Source: Public Health Intelligence Team

3.4.1.2 Attainment

Overall, at Key Stage (KS) 2 to 4, the gap between SEN and non SEN pupils in East Sussex has increased in both Maths and English (Figures 14 and 15). Attainment for pupils with Statements has improved between 2010 and 2012, yet for SAP and SA it has fallen notably over the last year. A significant improvement in attainment of non-SEN pupils in maths has contributed to the increased gap between SEN and non-SEN pupils.
Foundation Stage/Key Stage 1

The gap in attainment at Foundation Stage between SEN and non-SEN pupils increased between 2011 and 2012 from 37% to 48%. There was a corresponding decrease in East Sussex in the percentage of SEN pupils achieving at least 78 points and 6+ in all Personal, social and emotional development (PSED) and Communication, language and literacy (CLL) from 19% (21% nationally) in 2011 to 16% (23% nationally) in 2012. At KS1, overall attainment of SEN pupils fell in East Sussex in Reading, Writing and Maths against a increase in the attainment of SEN pupils nationally. The gap increased between the percentage of SEN pupils and non-SEN pupils achieving L2B+ (expected level of achievement at end of second year) in Reading, Writing and Maths in 2012 compared to 2011. Achievement in all subjects apart from Science (+0.5%) is lower than the national average by over 5 percentage points for reading and writing. The greatest gap between SEN and non-SEN pupils is in writing, reflecting the national picture.

Key Stage2/Key stage 4

Due to the changes in the test arrangements in English, results for 2012 are not comparable to previous years. In Maths the percentage of SEN pupils achieving expected progress (L4+) at KS2 increased from 48% (49% national) in 2011 to 50% (55% national) but the gap between SEN and non-SEN pupils increased from 41.5% to 44%. Those without SEN are nearly two and a half times more likely that those with SEN to achieve expected levels in maths and English, mirroring national patterns. Attainment has improved for those on SA (1.4%) and SAP in English (5.8%), and for statements in Maths (0.9%). However, attainment for those on SA and SAP has decreased for maths by 0.3% and 3% respectively, and by 1.4% in English for those with statements. Attainment in both subjects is slightly below national average for all SEN. At KS4 the attainment gap between SEN and non-SEN pupils has increased steadily between 2010 and 2012 from 50% to 52% for achievement of 5+ A*-C grades. For 5+ A*-G grades the gap between non-SEN and SEN pupils has increased from 27% to 35%. For all measures, East Sussex attainment for SEN pupils is markedly below the national average.

3.4.1.3 Attendance

In Comparison to our statistical neighbours, pupils in East Sussex have poor absence records across both primary and secondary schools and have the highest absence of all areas for both persistent absence and total absence (figures 16 and 17), 0.3% above the national average for primary and 0.9% for secondary schools.151

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151 East Sussex Inclusion support Services (October 2013)
For both authorised and unauthorised absence, primary and secondary pupils with SEN are more likely to be absent than those without SEN (table 8). However, while absence rates in primary school generally increase as the severity of need increases, in contrast secondary school pupils on School Action Plus are more likely to be absent, and be persistent absentees than either those with no SEN or those with School Action or a Statement. Primary pupils with SEN are 30% more likely than those without SEN to be absent, and are two and a half times more likely to be a persistent absentee. Secondary school pupils with SEN are 40% more likely to be absent, and nearly three times more likely to be a persistent absentee. Secondary School pupils on SAP are nearly 2.5 times more likely to be absent than those with no SEN, and nearly 4 times more likely persistent absentees.

Table 8: 2011/12 Primary and secondary school absence by SEN type and type of absence

<table>
<thead>
<tr>
<th>2011/12 Primary and Secondary School Absence Figures</th>
<th>No. of enrolments aged 5+</th>
<th>Authorised Absences (%)</th>
<th>Unauthorised Absences (%)</th>
<th>Persistent Absentees (no.)</th>
<th>Persistent Absentees (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary School</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non SEN</td>
<td>23,016</td>
<td>4.3</td>
<td>3.8</td>
<td>0.5</td>
<td>681</td>
</tr>
<tr>
<td>School Action</td>
<td>3,976</td>
<td>5.6</td>
<td>4.6</td>
<td>0.9</td>
<td>240</td>
</tr>
<tr>
<td>School Action Plus</td>
<td>2,163</td>
<td>6.4</td>
<td>5.3</td>
<td>1.1</td>
<td>193</td>
</tr>
<tr>
<td>Statement</td>
<td>639</td>
<td>7.4</td>
<td>6.6</td>
<td>0.9</td>
<td>79</td>
</tr>
<tr>
<td>Not Known²</td>
<td>668</td>
<td>12.8</td>
<td>7.4</td>
<td>5.4</td>
<td>44</td>
</tr>
<tr>
<td>All SEN</td>
<td>6,778</td>
<td>6.0</td>
<td>5.0</td>
<td>1.0</td>
<td>512</td>
</tr>
<tr>
<td><strong>Secondary School</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non SEN</td>
<td>16,800</td>
<td>5.6</td>
<td>4.8</td>
<td>0.8</td>
<td>1,031</td>
</tr>
<tr>
<td>School Action</td>
<td>2,556</td>
<td>8.1</td>
<td>6.2</td>
<td>1.8</td>
<td>335</td>
</tr>
<tr>
<td>School Action Plus</td>
<td>1,233</td>
<td>12.5</td>
<td>8.9</td>
<td>3.7</td>
<td>294</td>
</tr>
<tr>
<td>Statement</td>
<td>473</td>
<td>9.3</td>
<td>7.2</td>
<td>2.1</td>
<td>84</td>
</tr>
<tr>
<td>Not Known²</td>
<td>333</td>
<td>29.4</td>
<td>16.2</td>
<td>13.2</td>
<td>83</td>
</tr>
<tr>
<td>All SEN</td>
<td>4,262</td>
<td>9.5</td>
<td>7.1</td>
<td>2.4</td>
<td>713</td>
</tr>
</tbody>
</table>

*pupils having 38 or more half days of absence (authorised & unauthorised.) across both terms

**3.4.1.4 Exclusions**

East Sussex is a “high excluding” local authority compared to the national average, with exclusions disproportionately weighted towards primary schools (27% compared to 11% nationally) and to children with SEN (23% compared to 8% nationally). In 2008/09 East Sussex was the 19th highest excluding authority (out of 150) for fixed term exclusions and 56th highest for permanent exclusions. As with absence figures, East Sussex is the poorest performing of all statistical neighbours in relation to permanent exclusions from school (Figures 18 and 19), and also has some of the higher rates for fixed term exclusions across primary and secondary school. Of those referred to inclusion services,
70% had SEN, 51% of whom were at school action plus.  

A local 2012 scrutiny review of school exclusions found the majority of exclusions to be due to “defiance”, and suggests many exclusions could be avoided if high excluding schools took responsibility for managing a wider range of behaviours. The review also found that, while schools made adequate provision for pupils with physical disabilities, there is no comparable level of provision for pupils with behaviour related SEN.

In the 2012-13 school year there were 1,200 pupils with SEN who had fixed term exclusions (FTE) in East Sussex, 170 primary school pupils and just over 1,000 secondary school pupils: a total of just under 2,600 separate exclusions (an average of 2.1 exclusions per pupil). The most common reasons for FTE amongst SEN primary school pupils were physical assault to staff (19%); Defiance to Teachers (17%); Physical assaults to pupils (17%) and Persistent disruptive behaviour (16%). Amongst SEN secondary school pupils these were: defiance to teachers (23%); verbal abuse to staff (16%); physical assault to pupils (12%) and persistent disruptive behaviour (9%).

In 2012/13, 16 primary school pupils and 69 secondary school pupils with SEN were permanently excluded. The most common reason for permanent exclusion for both primary and secondary school children with SEN is persistent disruptive behaviour, which mirrors national findings. The majority of pupils excluded from primary (74%) and secondary (66%) were male and many were in receipt of FSM, an indication of low income and proxy for deprivation. Pupils with a statement of SEN are more likely than SA or SAP in primary school to get permanently excluded, yet this cohort had the least exclusions in secondary school.

3.4.1.5 Home to school transport
There are currently 1,000 children with SEN who are transported daily by the County Council to and from school for reasons of SEN referrals, child health, parental health, emotional fragility or inability to attend school and needing flexible learning options.

3.4.2 Not in Education, Employment or Training (NEET)
In August 2013 there were 1,350 young people who were NEET and have or had previously been on SA/SAP or had statements. This compares to 1,200 young people with no SEN and 100 young people with LDD but no statement. The majority of this population of SEN young people are seeking employment, education and training (47%). The proportion of young people with SEN who are NEET and have never been economically active (13%) is currently 65 times the proportion of equivalent non-SEN young people who are NEET (0.2%), and the proportion of SEN young people who are NEET and work ‘not for reward’ (2.3%) is nearly six times that of non-SEN young people who are NEET (0.4%). Young people with SEN who are NEET (120) are a third as likely as non-SEN young people who

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152 East Sussex Inclusion support Services (October 2013)
153 Children’s Services Scrutiny Committee (July 2012) Scrutiny review of school exclusions in East Sussex – Report by the project board
154 East Sussex County Council (2013) Education Support, Behaviour & Attendance Team
are NEET (350) to support family or be teen parents (120).

<table>
<thead>
<tr>
<th>SEN Category</th>
<th>2012</th>
<th>2013</th>
<th>% difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>57</td>
<td>59</td>
<td>-0.8</td>
</tr>
<tr>
<td>Emotional Behavioural Difficulties</td>
<td>391</td>
<td>531</td>
<td>4.0</td>
</tr>
<tr>
<td>Hearing Impairment</td>
<td>12</td>
<td>11</td>
<td>-0.3</td>
</tr>
<tr>
<td>Moderate learning difficulties</td>
<td>221</td>
<td>261</td>
<td>-0.8</td>
</tr>
<tr>
<td>Multi-Sensory difficulties</td>
<td>*</td>
<td>*</td>
<td>0.0</td>
</tr>
<tr>
<td>Physical difficulties</td>
<td>49</td>
<td>43</td>
<td>-1.3</td>
</tr>
<tr>
<td>Profound Learn difficulties</td>
<td>10</td>
<td>*</td>
<td>-0.6</td>
</tr>
<tr>
<td>Severe Learning difficulties</td>
<td>96</td>
<td>88</td>
<td>-2.3</td>
</tr>
<tr>
<td>Specific Learn difficulties</td>
<td>117</td>
<td>167</td>
<td>1.8</td>
</tr>
<tr>
<td>Speech and Language</td>
<td>49</td>
<td>64</td>
<td>0.3</td>
</tr>
<tr>
<td>Visual Impairment</td>
<td>*</td>
<td>*</td>
<td>-0.2</td>
</tr>
<tr>
<td>Other</td>
<td>45</td>
<td>58</td>
<td>0.2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>1,051</strong></td>
<td><strong>1,289</strong></td>
<td><strong>1.8</strong></td>
</tr>
</tbody>
</table>

Source: East Sussex Children’s Services 2013

Over 40% of young people with SEN who are NEET have emotional or behavioural difficulties, 20% moderate learning difficulties and 13% specific learning difficulties (table 9). In comparison to 2012 figures, this is a 4% increase in emotional or behavioural difficulties, and a 1.8% increase in specific learning difficulties, with severe learning difficulties and physical difficulties falling by 2.3% and 1.3% respectively.

In East Sussex there are currently over one and a half times more young SEN males than SEN females who are NEET, similar to 2012 figures. Nearly one third (32%) of NEET young people with SEN live in Hastings, over a quarter (27%) in Eastbourne, 18% in Lewes, 14% in Rother and 9% in Wealden, consistent with 2012 figures.

**3.4.3 Transition**

The social Care Transition Service is for young people aged 16-25 who have SEN and are eligible for adult social care. As at August 2013 there were 130 young people supported by the service, the majority referred from the Child Disability Service at age 16. The Transition team supports young people from Year 11 onwards who have severe and enduring disabilities and a statement of SEN, and are aware of the young people from 14 years of age (Figure 20 shows the East Sussex Transition Pathway). Social Workers support complex and LAC cases while less complex cases are supported by resource officers. These individuals remain the allocated worker for the young person until the age of 19 or until 25 years if appropriate. Those assessed as stable are referred to the localities teams at 19 years. 124

Between 2005 and 2012 there were approximately 900 moving on plans developed for children and young people with a statement or with a learning disability who reached statutory school leaving age. Around 500 of these young people remain in some kind of formal learning, the majority of whom (390) are in Further Education College (Table 10). 155

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155 East Sussex County Council (April 2013) Joint Commissioning for Children and Young People with SEN and Disability
<table>
<thead>
<tr>
<th>Situations</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment No Training to NVQ2 level</td>
<td>62</td>
</tr>
<tr>
<td>Employment/Training to NVQ2 level &amp; above</td>
<td>35</td>
</tr>
<tr>
<td>FE College</td>
<td>387</td>
</tr>
<tr>
<td>Higher Education</td>
<td>15</td>
</tr>
<tr>
<td>NEET</td>
<td>160</td>
</tr>
<tr>
<td>Not Known</td>
<td>58</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
</tr>
<tr>
<td>School Sixth Form</td>
<td>72</td>
</tr>
<tr>
<td>Sixth Form College</td>
<td>25</td>
</tr>
<tr>
<td>Statutory Education</td>
<td>1</td>
</tr>
<tr>
<td>Unknown</td>
<td>19</td>
</tr>
<tr>
<td>Work Based Learning</td>
<td>36</td>
</tr>
<tr>
<td>Total</td>
<td>878</td>
</tr>
<tr>
<td>Number still in formal learning</td>
<td>500</td>
</tr>
</tbody>
</table>

*Source data: ASPIRE*
3.4.4 Social care

CareFirst is the social care database collecting, recording and monitoring people who receive social care services in East Sussex. As at Mid-August 2013, 1,100 children and young people with SEN were supported by social care. Of this number, 320 were at School Action, 350 at School Action Plus and 430 had a statement of SEN. Of those at School Action Plus, young people with BESD were almost three times as likely as any other SEN type to have social care support (45%), followed by those with mild learning disabilities (16%) or speech, learning and communication needs (16%). Of those with a statement, children with severe learning difficulties were most likely to have social care support (22%), followed by BESD (22%) and mild learning difficulties (13%) (Figure 21).

Figure 20: East Sussex transition pathway

Source: East Sussex County Council
Boys (n=700) are more likely than girls (n=400) across all SEN provision to receive social care support, and those with a statement of SEN (300) are over twice the number receiving social care support than girls with a statement (120), which is expected given the increased likelihood of boys having SEN in comparison to girls. Girls with SAP are most likely to have BESD (46%) or MLD (20%) and those with a statement are most likely to have SLD (27%) or MLD (15%). Across both SAP and Statements, boys are most likely to have BESD (46% and 26%) followed by SLCN (20%) for those with SAP and SLD for those with statements (21%). Of those receiving social care support, 91% of those with SAP, and 93% of those with a statement are White or White British. Of the total numbers of children with SAP or a statement receiving social care support, the highest percentages of any Black or Minority Ethnic Group are seen in those with Any Other Mixed Background (1.7% and 1.6% respectively).

Of those with a statement, the 12-14 year age group are most likely to receive social care, while for School Action plus the highest usage is for 6 year olds and with School Action are those aged between 6 and 9 years, with another peak at 12 years. Numbers have been removed for those aged under 5, and those aged 17 on SA or SAP as these were less than 5 (Figure 22) and caution must be used when interpreting this data as this is a service snapshot and as such does not indicate trends.

Just over 3 in 10 children supported by Social Care have SEN: 9% School Action; 10% School Action Plus and 12% with a Statement. Approximately two fifths of those on School Action or School Action Plus are supported by the Family Support Team, while two fifths of those with a statement are supported by the Children with Disabilities Duty or Social Work Teams. Outside of the caseload of the disabilities teams, teams with the greatest percentage of SEN children and young people in their

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156 East Sussex Children’s Services (August 2013)
total caseload are the Looked After Children Team (44%) and T3 Transition Team (48%) (Table 11).

### Table 11: Type of Social Care Support received by type of SEN provision

<table>
<thead>
<tr>
<th>Service</th>
<th>School Action</th>
<th>School Action Plus</th>
<th>Statement of SEN</th>
<th>% of total caseload who are SEN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care Leavers Services</td>
<td>*</td>
<td>10</td>
<td>*</td>
<td>8%</td>
</tr>
<tr>
<td>Children With Disabilities Duty</td>
<td>*</td>
<td>105</td>
<td>74%</td>
<td></td>
</tr>
<tr>
<td>Children With Disabilities Soc Work Team</td>
<td>*</td>
<td>*</td>
<td>75</td>
<td>62%</td>
</tr>
<tr>
<td>County Adoption And Permanence Team</td>
<td></td>
<td></td>
<td></td>
<td>0%</td>
</tr>
<tr>
<td>Duty &amp; Assessment Team</td>
<td>47</td>
<td>31</td>
<td>14</td>
<td>20%</td>
</tr>
<tr>
<td>Family Plus Team</td>
<td>28</td>
<td>16</td>
<td>15</td>
<td>24%</td>
</tr>
<tr>
<td>Family Support Team</td>
<td>138</td>
<td>136</td>
<td>44</td>
<td>24%</td>
</tr>
<tr>
<td>Lac</td>
<td>32</td>
<td>56</td>
<td>65</td>
<td>44%</td>
</tr>
<tr>
<td>T3 Transition</td>
<td></td>
<td></td>
<td>63</td>
<td>48%</td>
</tr>
<tr>
<td>Under 19 Substance Misuse Service</td>
<td></td>
<td></td>
<td>*</td>
<td>50%</td>
</tr>
<tr>
<td>Youth Offending Team</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Youth Support Team</td>
<td>72</td>
<td>92</td>
<td>46</td>
<td>38%</td>
</tr>
<tr>
<td><strong>Grand Total</strong></td>
<td><strong>322</strong></td>
<td><strong>347</strong></td>
<td><strong>430</strong></td>
<td><strong>31%</strong></td>
</tr>
</tbody>
</table>

*NB: numbers under 5 have been removed

### 3.4.5 Vulnerable children

Of the 780 children and young people aged 19 years and under who are School Action Plus or have a statement and are currently supported by social care services, nearly two thirds (64%) are Children in Need (CIN), 13% have a Child Protection order (CP), 22% are Looked after children (Lac) and 0.6% are Looked After Children with a Child Protection order* (Table 12).157

### Table 12: SEN provision by type of social care case

<table>
<thead>
<tr>
<th>No SEN</th>
<th>CIN (581)</th>
<th>CP (141)</th>
<th>Lac (84)</th>
<th>Grand Total (809)</th>
</tr>
</thead>
<tbody>
<tr>
<td>School Action</td>
<td>206</td>
<td>64</td>
<td>49</td>
<td>322</td>
</tr>
<tr>
<td>School Action Plus</td>
<td>199</td>
<td>57</td>
<td>88</td>
<td>344</td>
</tr>
<tr>
<td>Statement of SEN</td>
<td>295</td>
<td>25</td>
<td>106</td>
<td>426</td>
</tr>
<tr>
<td><strong>Total SEN</strong></td>
<td><strong>700</strong></td>
<td><strong>146</strong></td>
<td><strong>243</strong></td>
<td><strong>1089</strong></td>
</tr>
</tbody>
</table>

*NB: numbers of Lac with a CP order are too small to show by SEN provision

### Table 13: Percentage of each type of social care case by type of SEN

<table>
<thead>
<tr>
<th>CIN (%)</th>
<th>CP (%)</th>
<th>Lac (%)</th>
<th>Grand Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD</td>
<td>8</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>BESD</td>
<td>26</td>
<td>39</td>
<td>47</td>
</tr>
<tr>
<td>MLD</td>
<td>13</td>
<td>20</td>
<td>16</td>
</tr>
<tr>
<td>OTH</td>
<td>2</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>PD</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>PMLD</td>
<td>10</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>SLCN</td>
<td>13</td>
<td>19</td>
<td>10</td>
</tr>
<tr>
<td>SLD</td>
<td>17</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>SPLD</td>
<td>8</td>
<td>13</td>
<td>7</td>
</tr>
<tr>
<td>VI</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

*NB: numbers of Lac with a CP order are too small to show by SEN provision

**Source:** CareFirst, August 2013

157 East Sussex Children’s Services (August 2013)
Behavioural, Emotional and Social Difficulties (BESD) are the most prevalent type of SEN across CIN (26%), those with a CP order (39%) and LAC (47%) (Table 13).

3.4.5.1 Children in Need
Of the 700 Children in Need in the county who have SEN, 200 are at School Action, 200 School Action Plus and 300 have a statement of SEN. The most prevalent SEN type within those who have a common assessment framework (CAF) is BESD (Figure 21). The greatest numbers of those with a statement are currently aged 12 and 16 years (Figure 23). This will have an impact on those entering the transition into adult services over the next couple of years. Of those Children in Need who have SEN, 85% are White British and 4% are of Mixed ethnicity.

3.4.5.2 Child protection (CP)
In 2011/12 the overall rate of Child Protection Plans per 10,000 (0 to 17 year olds) was 65 for East Sussex compared to the England average of 38, although the number has fallen since. Information on the age of the 150 children with SEN who have a Child Protection Order indicates that the highest numbers of children with School Action or School Action Plus are aged 6 to 10 years. The most prevalent type of SEN for those with a CP plan is BESD, followed by MLD. However, numbers are small and this is a service snapshot so information should be read with caution. 93% of those with SEN who are CP are White British.

3.4.5.3 Looked after children (LAC)
Looked after children, as defined by the Children Act 1989, are either looked after or in the care of a local authority, or are provided with accommodation for more than 24 hours by a local authority. Of the 240 children with SEN who have are Looked After, numbers with a statement rises for young people between the ages of 10 and 15, while those with SAP are most likely to be aged 15 years or older. However, as with Child Protection data, this is a service snapshot so should be read with caution as this could be a cohort effect. Of those who are LAC and have SEN, 90% are White British.
### 3.5 SUMMARY OF KEY LOCAL FINDINGS

<table>
<thead>
<tr>
<th>Area</th>
<th>Key Findings</th>
</tr>
</thead>
</table>
| **Local Population**        | - East Sussex has 27% of the population aged 25 years or under, lower than the South East (30%) and England (31%).  
                               - There is no expected rise in numbers of children with disabilities.  
                               - Complexity of need and demand on services is increasing.  |
| **Types of SEN and disability** | - In comparison to nationally:  
                                 o The rate of Moderate Learning Difficulty is lower than nationally but is rising faster (from 2.29 per 1,000 in 2008 to 2.74 in 2012, compared to 3.60 to 3.65 nationally).  
                                 - The most prevalent type of SEN for Children in Need (26%), those with a child protection order (39%) and Looked After Children (47%) is behavioural, emotional and social difficulties (BESD).  |
| **Education**               | - There are currently 13,500 children with SEN known to schools, a rise of 4.4% from the number of children with SEN known to schools in 2004 (12,700).  
                               - Against declining national trends, the number of the school population with statements locally has increased.  
                               - Since 2004 there has been a continuous upward trend in SEN provision for:  
                                 o Autism spectrum disorder (ASD) (340 pupils in 2004 to 600 in 2013).  
                                 o Visual impairments (VI) (25 pupils in 2004 to 30 in 2013).  
                                 o Profound and multiple learning difficulties (PMLD) (10 pupils in 2005 to 30 in 2013).  
                                 o Speech language and communication needs (SLCN) (370 pupils in 2004 to 580 in 2013).  
                                 - In contrast to rising national trends, KS1 attainment of SEN pupils has fallen in East Sussex in reading, writing and maths.  
                                 - Overall, at Key stages 2-4, there is an increasing gap between SEN and non SEN pupils in both Maths and English.  
                                 - East Sussex has the poorest rates of exclusion and absence amongst our statistical neighbours, with exclusions weighted towards: primary schools and children with SEN. |
| **Wider Determinants**      | - The number of young people claiming Disability Living Allowance is rising with girls increasing nearly twice as fast as boys, although 70% DLA claimants under 16 are boys.  
                               - One in four children with a child protection plan have a special educational need and despite recent decline, the rate of Child Protection Plans in East Sussex (65 per 10,000) remains almost twice that of England (37.8 per 10,000).  
                               - There is a correlation between the distribution of SEN and areas of deprivation.  
                               - Over two fifths of SEN young people who are NEET (530 or 41%) have emotional or behavioural difficulties, representing a 4% increase from 2012.  
                               - The percentage of mothers smoking at time of delivery (16%) is higher than both regionally (13%) and nationally (13%).  
                               - The percentage of babies born with low birth weight (7%) is slightly higher than nationally (6.5%).  
                               - A higher percentage of mothers initiate breastfeeding in East Sussex (80%) than regionally (78%) and nationally (74%).  
                               - Exclusion in primary school for SEN pupils has increased significantly in recent years and is a growing problem. |
Local population projections (Figure 24) suggest that by 2027 the population of East Sussex will increase by approximately 4% from 531,200 to 553,300, equating to a 5.6% increase in males and 2.8% increase in females in the county. However, the 0 to 24 year old population is projected to decrease over the same period by 5.7% from 143,200 to 135,000. The main expected fall in population is in the 0 to 4 cohort (-0.7%) and the 15 to 24 cohort (-1.5%). The 5 to 14 year old population is also expected to decrease across the county, with the exception of Hastings and Rother where slight increases are expected (0.1% and 0.4% respectively). The 40 to 54 cohort is also expected to decrease by 4.5% by 2027. Conversely, the population aged 30 to 39 will increase across the county with the exception of Eastbourne (-1.2%) and Hastings (-0.8%). The 55+ population is projected to increase by 6.8%, the greatest increases are expected in Eastbourne (7.4%).

Over the last 30 years the disabled population increased by 70% (1976 to 2006) with the fastest growing proportion of this population being the under 16 age group. The number of children born with complex needs and surviving into adolescence and beyond is also increasing. Evidence suggests that services are faced with higher numbers of children with complex needs than they have ever experienced previously. While children with disabilities and complex health needs have been better enabled to survive, provision has not kept up with modern developments and has resulted in many children not being supported to achieve their potential.

Overall in East Sussex the percentage of 10 to 17 year olds with a disability is predicted to stay the same at 3.9%, but the percentage with sight disability is predicted to decrease from 1.2% to 1.1%. Lewes district is estimated to see the greatest variation in rates of disability with a 0.1% increase in overall disability, higher severity disability, and hearing disability, and a 0.1% decrease in locomotor disability, and sight disability. Hastings is also estimated to see a decrease of 0.1 rate per 100 for

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158 ESCC projections, July 2013 http://www.eastsussexinfigures.org.uk/
However, these changes in rate do not equate to an increase in the number of children aged 10 to 17 years with a disability due to the predicted decrease in this cohort by 2027.

**Projecting adult needs and service information system (PANSI)**

The Department of Health *Projecting Adult Needs and Service Information System* (PANSI) looks at how demography and certain conditions can impact on populations aged between 18 and 64 years. Whilst there is no complimentary system for those under the age of 18 years, examination of PANSI population projections for 18 to 24 year olds in East Sussex will give an indication of the level of need for this cohort when they are of younger ages and using children’s services. The evidence suggests that prevalence of many types of disability in the 18 to 24 age group will decrease between 2012 and 2020, however it is not possible to extrapolate much from this data as current predictions do not go beyond 2020. Table 14 outlines current predictions for different types of disability in more detail.

<table>
<thead>
<tr>
<th>Table 14: People aged 18 to 24 predicted to have SEND, by type of need projected to 2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning Disability Baseline estimate</td>
</tr>
<tr>
<td>Number of 18-24 years olds</td>
</tr>
<tr>
<td>Learning Disability</td>
</tr>
<tr>
<td>Baseline estimate</td>
</tr>
<tr>
<td>Moderate or severe Learning Disability</td>
</tr>
<tr>
<td>Moderate Hearing Impairment</td>
</tr>
<tr>
<td>Physical Disability (Moderate or severe)</td>
</tr>
<tr>
<td>Physical Disability</td>
</tr>
<tr>
<td>Moderate Hearing Impairment</td>
</tr>
<tr>
<td>Visual Impairment</td>
</tr>
<tr>
<td>Downs Syndrome</td>
</tr>
<tr>
<td>Autism Spectrum Disorder</td>
</tr>
<tr>
<td>2012 age of cohort</td>
</tr>
<tr>
<td>18 to 24</td>
</tr>
<tr>
<td>16 to 22</td>
</tr>
<tr>
<td>14 to 20</td>
</tr>
<tr>
<td>12 to 18</td>
</tr>
<tr>
<td>10 to 16</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2012</th>
<th>2014</th>
<th>2016</th>
<th>2018</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>1,045</td>
<td>1,011</td>
<td>980</td>
<td>949</td>
<td>910</td>
</tr>
<tr>
<td>241</td>
<td>234</td>
<td>228</td>
<td>221</td>
<td>213</td>
</tr>
<tr>
<td>1,886</td>
<td>1,827</td>
<td>1,774</td>
<td>1,720</td>
<td>1,652</td>
</tr>
<tr>
<td>56</td>
<td>54</td>
<td>51</td>
<td>50</td>
<td>49</td>
</tr>
<tr>
<td>25</td>
<td>24</td>
<td>24</td>
<td>23</td>
<td>22</td>
</tr>
<tr>
<td>24</td>
<td>23</td>
<td>23</td>
<td>22</td>
<td>21</td>
</tr>
<tr>
<td>392</td>
<td>380</td>
<td>368</td>
<td>358</td>
<td>343</td>
</tr>
</tbody>
</table>

Source: PANSI, 2013

Estimates from PANSI indicate that:

**Physical disability**
- Population projections imply that in the short term there may be decreasing numbers of children and young people aged under 25 years needing support for moderate or severe physical disabilities. The total population of 18 to 64 year olds with physical disability is predicted to increase slightly for both moderate and severe disabilities, although the increases are predicted mainly for those aged 55 to 64 years and as such should not impact on children’s services.
- The rate of central nervous system anomalies has declined nationally but increased in the South East.

**Profound and multiple learning difficulties**
- There has been a year on year upward trend in pupils with SEN provision for profound and multiple learning difficulties since 2004 although numbers remain relatively low compared to other SEN needs.

**Speech language and communication needs**
- There has been a year on year upward trend in pupils with SEN provision with Speech Language and Communication Needs since 2004.

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161 ESCC projections, July 2013 http://www.eastsussexinfigures.org.uk/
Moderate hearing impairment
- The total population of 18 to 64 year olds with moderate hearing impairment is predicted to increase slightly from 13,500 in 2012 to 14,400 in 2020, although the increases are predicted for later onset in older age groups and as such shouldn’t impact on children’s services.

Visual impairment
- There has been a year on year upward trend in pupils with SEN provision with Visual Impairments since 2004 although numbers remain relatively low in comparison to other types of SEN need.
- The total population of 18 to 64 year olds with visual impairment is predicted to remain similar with no real increase by 2020.

Learning disability
- 2009 national research indicates the numbers of young people with mild to moderate learning disabilities will increase by more than 50% by 2018 as more people become known to, and start using, social services.
- The rate of young people with moderate Learning Difficulties in East Sussex is rising out of proportion to both regional and national rates.

Downs syndrome
- In 2010 the South East had the second highest percentage of prenatally diagnosed Downs Syndrome babies in the UK, although it’s likely that many of these pregnancies will be terminated.
- While there is a predicted drop in numbers of 18 to 24 year olds with Downs Syndrome between 2012 and 2020, the total population of 18 to 64 year olds with Downs Syndrome is predicted to stay relatively stable between 2012 and 2020 at 188/189 people in East Sussex.

Evidence outlined in this needs assessment indicates that:

Autistic spectrum disorders (ASD)
- There has been a continuing year on year upward trend of pupils with SEN provision with ASD from 340 in 2004 to 600 in 2013.

Poverty
- National evidence shows that across the UK child poverty is increasing and children and young people with disabilities are disproportionately affected.
- Despite a decreasing younger population, DLA claimants for under 16s are steadily increasing.

Education
- Since 2010 SA and SAP provision have declined, yet the number of children with statements has risen in the same time period. This is particularly prevalent in primary schools and is against national trends.
- At KS1, overall attainment of SEN pupils in East Sussex fell in Reading, Writing and Maths against an increase in the attainment of SEN pupils nationally. The gap increased between the percentage of SEN pupils and non-SEN pupils achieving L2B+ in Reading, Writing and Maths in 2012 compared to 2011.
- Overall, at KS2-4, the gap between SEN and non SEN pupils has increased in both Maths and English. Attainment for pupils with Statements has improved recently, yet for SAP and SA has fallen notably.
- For all measures at KS4 East Sussex attainment for SEN pupils is markedly below the national average.

Exclusions
- East Sussex is a “high excluding” LA compared to nationally, with exclusions disproportionally weighted towards primary schools (27% compared to 11%) and to children with SEN (23% compared to 8%). In 2008/09 East Sussex was the 19th highest excluding authority (out of 150)
for FTE and 56th highest for PE.

- A 2012 scrutiny review of school exclusions found that, while East Sussex provides a high level of good quality special needs places, they are consistently oversubscribed.\(^{162}\)

**NEET**

- In comparison to 2012 figures, there has been a 4% increase in NEET SEN young people who have emotional or behavioural difficulties, and a 1.8% increase in specific learning difficulties, while numbers with severe learning difficulties and physical difficulties have fallen by 2.3% and 1.3% respectively.

**Looked after children**

- The numbers of safeguarding referrals for children with disabilities has increased over recent years and there a rising demand for placement outside the family with corresponding rises in ESCC Foster Care referrals against a decline in Agency Foster Care Referrals.

**Equipment**

- The number of technologically dependent children being cared for at home has increased significantly since 2011, reflecting both improving technology and increasing clinical expertise. However these children will move into adult services soon and research suggests few specific services currently exist to do this.

**Short breaks and leisure**

- There is increasing demand for short break services, with the greatest increases in number of attendees and hours of provision seen by Autism Sussex and SCOPE

### 4.1 SUMMARY OF FUTURE NEEDS

\(^{162}\) Children’s Services Scrutiny Committee (July 2012) Scrutiny review of school exclusions in East Sussex: Report by the project board
5.1 How services are commissioned

East Sussex has a long history of partnership working, and some priority children’s services have been jointly commissioned for the last 3 years. The ambition to integrate commissioning for children with SEND started with the Early Years Support programme. Now, with the advent of the national reforms for children with SEND, the strategic direction is to bring together the commissioning responsibilities of the three East Sussex Clinical Commissioning groups (CCGs) for children’s continuing healthcare with the Local Authority’s responsibilities for social care and education. In the longer term, other aspects of healthcare services are likely to be included such as children’s therapy, equipment and seating, and incontinence aids.\textsuperscript{163}

5.2 Evaluation of SEND pathfinder programme

At the 30th of August 2013, 58 families had been recruited to the SEND pathfinder programme and were eligible for EHC plans, over half of whom (57%) were aged 4-11 years. Of this cohort, 40% have communication and interaction needs, 40% have sensory and/or physical needs, 15% have cognitive and learning needs and 5% have behavioural, emotional and social development needs; 90% (52 families) have started the new assessment/planning process, and 85% (49) have a completed plan. By the 30\textsuperscript{th} September 2013 the aim is to have a minimum of 165 families with completed plans in place.\textsuperscript{164}

5.3 Children’s disability service

The Children’s disability service (CDS) has two main strands of support: social work, and community resources. Services provided include: direct intervention; spectrum (helping young people with ASD access leisure), sibling service; overnight provision; short break overnight services; direct payment services; after school and holiday clubs (managed in-house) and nursery provision for children with complex needs. An early intervention service is currently being developed to support young people who need a lower level of support or who do not meet criteria for specialist services. Housing adaptations will remain in-house rather than join the equipment service provision in Kent.

CDS currently supports 275 children and young people with disabilities in the county. Of these 150 children are supported by the Disability Duty Team and 125 by the Family Support Team and Looked After Children Service. The majority (nearly two thirds) of all those referred are Children in Need (Figure 25).

\begin{figure}[h]
\centering
\includegraphics[width=0.5\textwidth]{figure25.png}
\caption{Referrals to CDS 2012/13 by type of need}
\end{figure}

In 2012/13 there were 300 referrals to CDS, of which 145 were accepted and over half (52% - 155)

\textsuperscript{163} Strategic Lead for Health for Children and Maternity – East Sussex
\textsuperscript{164} Send Pathfinder Programme Manager
not accepted. From the information provided it was not possible to determine why such a high proportion of referrals did not result in a CDS action. However, it is likely that many did not meet referral criteria for the service. The Local Offer will clarify to parents and health and care professionals which services are most appropriate for children, depending on their circumstances, and provide greater signposting and transparency.

Of those referred the greatest proportion were aged between 10 and 14 years, with 11 year olds forming 10% of the overall cohort (Figure 26). This could be connected to referral during the move up to secondary school, and indicates that there is likely to be a cohort effect impacting on transition services over the next couple of years.

Currently, the most prevalent disability for those referred is ASD/Aspergers Syndrome (18%) followed by learning disability (13%). Young people with personal care difficulties, visual or hearing disabilities are least likely to be referred (3% combined), however for one third of referrals data was not recorded.¹⁶⁵

The number of SEN agency placements increased for all SEN types between 2010/11 and 2011/12, with the exception of severe learning difficulties. The greatest increase has been for those with moderate learning difficulties (114%).¹⁶⁶ The median cost of SEN agency placements increased between 2010/11 and 2011/12 (Table 15). During this period the greatest median costs were for Behaviour, Emotional and Social Difficulties (£49,500), Moderate Learning Difficulties (£44,800) and Visual Impairment (£44,700).

<table>
<thead>
<tr>
<th>SEN category</th>
<th>Median Cost 2010/11</th>
<th>Median Cost 2011/12</th>
<th>% change</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD</td>
<td>£39,000</td>
<td>£39,700</td>
<td>+2%</td>
</tr>
<tr>
<td>BESD</td>
<td>£43,500</td>
<td>£49,500</td>
<td>+14%</td>
</tr>
<tr>
<td>MLD</td>
<td>£28,800</td>
<td>£44,800</td>
<td>+56%</td>
</tr>
<tr>
<td>PD</td>
<td>£31,300</td>
<td>£31,500</td>
<td>0%</td>
</tr>
<tr>
<td>SLCN</td>
<td>£24,800</td>
<td>£33,500</td>
<td>+35%</td>
</tr>
<tr>
<td>SLD</td>
<td>£43,300</td>
<td>£43,500</td>
<td>0%</td>
</tr>
<tr>
<td>SPLD</td>
<td>£19,400</td>
<td>£19,400</td>
<td>0%</td>
</tr>
<tr>
<td>VI</td>
<td>£45,300</td>
<td>£44,700</td>
<td>-1%</td>
</tr>
<tr>
<td>HI</td>
<td>£20,700</td>
<td>£34,200</td>
<td>+65%</td>
</tr>
<tr>
<td>MSI</td>
<td>n/a</td>
<td>£35,500</td>
<td>n/a</td>
</tr>
<tr>
<td>PMLD</td>
<td>£35,300</td>
<td>£31,500</td>
<td>-11%</td>
</tr>
</tbody>
</table>

¹⁶⁵ East Sussex Children’s Disabilities Services (Sept 2013)
¹⁶⁶ East Sussex County Council (2013) Children’s Services Portfolio Plan 2013/14 – 2015/16
5.3.1 Service satisfaction
The key outcome indicator for disabled children is “parental experiences of provided services”. It is scored out of 100 with higher scores reflecting greater satisfaction. In 2009/10 the national indicator score was 61/100 with East Sussex receiving a score of 60/100.

5.3.1.1 Complaints
There are three stages to the complaints process regarding any issues with Child Disability Services:

- **Stage 1** – an initial complaint or issue raised which will be dealt with within 10 days.
- **Stage 2** – if the complainant remains unhappy with the outcome they can escalate the complaint which involves investigation by an investigating officer and an independent officer
- **Stage 3** – if the complainant is still unhappy they can request the complaint goes to panel

Over the last three years there have been no stage 2 or 3 complaints to the service, and the number of formal stage 1 complaints and representations has been steadily falling (from 45 in 2010/11 to 27 in 2012/13). Numbers of complaints about specific services are small but there has been a slight increase for CITS and from parents of those with special educational needs (the latter falling from 65 in 2010/11 to 22 in 2011/12, before rising again to 53 in 2012/13).

For 2012/13, the most common complaints received from parents and carers regarding disability and SEN are outlined in table 16:

<table>
<thead>
<tr>
<th>Disabilities</th>
<th>SEN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insufficient support or lack of support, including respite care</td>
<td>Unhappy with school placement decision</td>
</tr>
<tr>
<td>Assessment content (comments and outcomes)</td>
<td>Delays with school placement</td>
</tr>
<tr>
<td>Social worker not taking agreed action</td>
<td>Child out of school</td>
</tr>
<tr>
<td>Separated fathers not being kept informed</td>
<td>Delays in Statement process</td>
</tr>
<tr>
<td>Lack of communication</td>
<td>Statements not being revised after reviews</td>
</tr>
</tbody>
</table>

*Source: Children’s Services Complaints Team 2013*

The 2012 Annual Participation and Consultation Report found that although the circumstances of complaints are on the whole very individual, commonalities included: concerns about levels of respite care, changes to school transport arrangements, provision of school places, decisions about school placements for children with special educational needs, decisions in relation to child protection, decisions in relation to care proceedings, levels of contact with children, and the quality of communication (lack of clarity, unhelpful communication or delays in responding). The report also noted the few but consistent complaints from fathers at the point of family breakdown feeling that they were not being listened to.

5.4 Health services
In East Sussex, prior to May 2013 there were two 24/7 in-patient paediatric facilities, one at the Conquest in Hastings and one in Eastbourne, each with a 15 bed in-patient paediatric facility with an assessment/observation area, supported by ENT, general surgery, urology and oncology. There was no designated area for in-patient young people aged 13 to 19 years, a national standard expected of all Trusts paediatric units. As part of temporary changes to Maternity and Paediatrics services at East Sussex Healthcare Trust, since May 2013 the in-patient unit at Eastbourne District General Hospital closed and the inpatient ward at the Conquest remains open 24/7 with 21 beds plus one oncology room— for children who require inpatient paediatric facilities. This can be increased to 26 plus one oncology room if required. The Special Care Baby Unit has also centralised from two sites to a single

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167 East Sussex County Council (September 2013) Children’s Services Complaints Team
site at the Conquest. Both sites maintain day surgery and outpatient clinics. These changes are expected to be in place for 18 months whilst work to decide on future reconfiguration is in progress.

### 5.4.1 Community paediatric services

Within Community Health services in East Sussex there are three main teams:

1. **Community Nurses** – East and West teams carry out nursing assessments for children with SEN or disabilities.
2. **Complex Needs Team**
3. **Paediatric Community Nursing team** for children with disabilities who have acute nursing needs that can’t be met elsewhere. This team provides respite, palliative care and bereavement services in conjunction with the community team.

In the East of the county the caseloads of children with ASD are higher than in the West of the county which has a relatively even split between Global Developmental Delay and ASD. Waiting times for community health services are one of the biggest complaints currently, with longer waiting lists in the West of the County than the East. During 2012/2013, Health Visitors had over 300,000 contacts with children and their parents.

#### 5.4.1.1 Community Wellchild Nurse:

The national increase in technology dependent children being cared for at home has resulted in a number of delays in children being discharged from hospital to home, particularly for those requiring long term ventilation and tracheostomy care. To improve discharge planning in East Sussex the Wellchild Nurse post was implemented in 2011 to reduce hospital admission and improve coordinated care delivery with enhanced patient outcomes. This has included developing multi-disciplinary discharge planning meetings and acting as the key professional overseeing and coordinating services, which has positively impacted on length of hospital stay for children. In addition the Wellchild nurse has addressed an increased need for training nursery, school and transport staff to care for children requiring suctioning, oxygen therapy, tracheostomy care and other specialist healthcare needs. Between 2011 and July 2013 the Wellchild Nurse supported:

- 18 children with tracheostomy at home,
- 5 children on a ventilator at home
- 10 children with acquired brain injuries at home
- 6 children total parenteral nutrition at home
- 15 children post operative support following orthopaedic surgery
- 79 children’s coordination of care/CHC assessment when admitted to local and tertiary hospitals
- 738 referrals to housing, equipment, wheelchairs and other services (CNN, social care, third sector)

#### 5.4.2 Continuing health care (CHC)

A continuing care package is required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone. It does not include children and young people with care needs that may be met appropriately through existing universal or specialist health services. Continuing Care for children and young people is organised differently than continuing care for adults, whose care need provision, whether at home or in a care home, is solely the responsibility of the NHS. A wide range of agencies are likely to be involved with a child or young person’s continuing care package will. Currently there are 32 children aged 1 to 18 years who receive CHC at a quarterly cost (Q2, 2013/14) of approximately £430,000, with individual support packages ranging from £171 a week to £9,300 a week for 24/7 home care nurse and support worker. This is a slight decrease from 34 children in Q1 of 2013/14.

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171 East Sussex Children’s Services (2013) Children’s Health Commissioning Team

172 Department of Health (2010) National Framework for Children and Young People’s Continuing Care

173 East Sussex Children’s Services (2013) Children’s Health Commissioning Team
5.4.3 Personal health budgets
A personal health budget can be used to help meet a child’s health and wellbeing needs, as defined by the child’s Health Outcomes Plan. That might include therapies, personal care, purchases, lifestyle advice or support that is not currently provided by the NHS, such as: music and play therapy; reflexology; additional physiotherapy; sensory toys or special equipment; leisure activities or hobbies; travel expenses to access services/activities; and respite care and support. Of the 32 children and young people who receive continuing health care, 9 receive Personal Health Budgets (PHBs) at an average quarterly cost of £59,000.174

5.4.4 Palliative care
Many children and young people with Special Educational Needs or Disabilities will have life limiting conditions.

5.4.4.1 Chestnut Tree House (community and in-house team)
Chestnut Tree House delivers palliative care for people aged 0-25 years across Sussex and South East Hampshire in homes, schools, hospitals and hospices. There are 21 staff within the community team and 58 staff within the in-house team.

A 2013 Care Quality Commission report found that all service standards were being met by Chestnut Tree House and parents reported that they were being treated with dignity and respect and were involved in aspects of their child’s care. Chestnut Tree House also scored highly in all areas of an NHS quality assurance report looking at Quality of Life, maintaining good health, being safe, making a contribution and economic wellbeing.175

5.4.4.2 Demelza children’s community palliative care service
Demelza delivers family support services and alternative therapies to 0 to 19 year olds who have a life-threatened or limited condition in East Sussex and parts of South West Kent. Care is delivered in homes, schools, hospitals and residential units. Between September 2010 and August 2013, 205 families have been supported by Demelza, 87 of which are still accessing support (42%), 82 of which have been discharged (40%) and 17 of which have been bereaved (8%).

5.4.4.3 Chailey Heritage clinical services
Chailey Heritage Clinical Services are part of South Downs Health NHS Trust and provide an assessment and treatment centre for children and young adults with physical disabilities and complex health needs within the UK. Services are offered at Chailey Heritage school (outlined later in the report), outpatient base at Chailey Heritage Clinical Services, at home, and overnight short services at home and at Chailey, and include: Clinical Services; Tertiary Outpatient Clinics; Specialist continuing care community services; Enhanced Residential Care through a four bed unit; Future Accommodation for 19-25 year olds; Rehabilitation Engineering Service; Research Team; and Acquired Head Injury services. As part of Chailey Heritage services a Family Liaison Officer provides workshops for parents around key issues. In 2012/13 there were 348 outpatient appointments for 151 children and young people across the county, 254 respite nights and 104 outreach nights provided for fewer than 10 children in the county. East Sussex funded 87 transitional service respite nights in 2012/13, with 401 funded privately. This snapshot is consistent with service use over the last three years.176

5.4.5 Integrated therapy services
An integrated therapy service is available to children and young people aged 0 to 19 years at an annual cost of £3.9 million. The Children’s Integrated Therapy Service (CITS) brings together all therapists which provides: speech and language therapy; occupational therapy; and physiotherapy. Five area teams support children and young people across the county: Lewes; Wealden; Eastbourne; Rother; and Hastings. The Children’s Integrated Therapy Service provides 3 key elements of service

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174 East Sussex Children’s Services (2013) Lead Nurse for Disabled Children & Young People
175 Care Quality Commission (April 2013) Inspection Report
176 Chailey Heritage (2013) Business Support team
delivery:

- **Universal services** - for all children and their families 0 to 16 years and 16 to 19 years in full time education, including: Information about services available; parental and professional advice, guidance and training (including settings and schools).
- **Targeted services** - for specific children and their families 0 to 16 years and 16 to 19 years in full time education, including: Specific advice and guidance to parents and practitioners; support to address language delay/impoverished language, SEN (less severe clinical needs), mild neurological problems, children under 11 with ASD and sensory processing.
- **Specialist services** – Including services for home adaptations/equipment and orthotics prescription; SEN and Disability (severe clinical need); Life limiting conditions; dysphagia (feeding/swallowing); Augmentative and Alternative Communication (high end need); Specialist assessment as part of the SENDIST process.  

Children can be referred by parents, carers, schools or other professionals if they have severe developmental difficulties including: cerebral palsy or other neuromuscular conditions; orthopaedic disorders; abnormalities of gait; respiratory disorders (for example cystic fibrosis); rheumatology; speech, language and communication needs; sensory processing difficulties; coordination and motor difficulties. Services are offered in a range of venues – and may use available Children’s Centres as well as Health Centres, schools and other community venues as appropriate. The CITS school-age element will offer a service from Year 1 (age 5+) to age 16 years. The area teams will support children within both special and mainstream schools as well as through the transition between the Early Years service and school-age provision.

<table>
<thead>
<tr>
<th>Therapy</th>
<th>New referrals</th>
<th>Accepted referrals</th>
<th>Priority referrals – therapy within 2-6 weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech and language therapy (SALT)</td>
<td>330</td>
<td>231 (70%)</td>
<td>40 (12%)</td>
</tr>
<tr>
<td>Occupational therapy (OT)</td>
<td>187</td>
<td>96 (51%)</td>
<td>16 (9%)</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>254</td>
<td>114 (45%)</td>
<td>62 (24%)</td>
</tr>
</tbody>
</table>

*Source: Kent Community Health Trust*

In the first quarter of 2013 the greatest number of referrals were for Speech and Language Therapy services (Table 17). The service has recently been redesigned to improve: data submission and coding; the utilising of assistant therapists; patient satisfaction information and access to suitable clinical space to provide efficient access to therapy services.  

5.5 Autistic spectrum disorder

In East Sussex multi-disciplinary Autism Spectrum Disorder Monitoring and Support Groups form part of the Inclusion Support Services in the County. There are two groups, one for the East of the county and one for the West, and there has been a year on year increase of families registered with the groups from 660 in 2012 to 790 in 2013 (+19%). The multi-agency ASD Monitoring and Support Groups run a comprehensive programme of training across East Sussex to meet the needs of professionals and parents, peer awareness in schools, a two-yearly conference for parents/carers of children with ASD was held on managing behaviour and a variety of short breaks including activity mornings, school trips and after school clubs.

In 2012, 26 professionals from a range of disciplines undertook five days of training on the Autistic Spectrum Diagnostic Schedule (ADOS-2) which is a conversation and play based observation tool that helps to identify behaviours associated with Autism. Educational Psychologists from across East Sussex have been using the ADOS-2 to support the multi-disciplinary process. Over the last year there have been 108 assessments, signifying that just under half of assessments (46%) led to diagnoses of Autism:

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177 East Sussex Children’s integrated therapy services (2013) NHS Standard Contract for community services: Service Specification

178 Children’s Joint Commissioning (2013) Q1 performance monitoring report
32 diagnoses of Autism
18 diagnosis of ASD
58 diagnoses of no autism.

A single information gathering form has also been introduced over the last year which is in use by education and health practitioners (including CAMHS, therapists, paediatricians and schools). A leaflet explaining these new processes has been co-produced with parents and published in the last year.

Autism Accreditation is an internationally recognised mark of excellent practice in the field of autism and is recognition that a school or setting meets a set of standards that ensure good autism practice and policy is embedded in every aspect of the work of that school or setting. Currently 12 schools and services in East Sussex have achieved Autism Accreditation

5.6 Residential care
There are five residential homes in East Sussex for disabled children, provided by both the local authority and the independent sector. All the homes both council and independent are registered with Ofsted and inspected twice yearly.

5.6.1 Acorns and Bungalow
Acorns and The Bungalow are East Sussex County Council maintained seven bedded residential units located in Bexhill and Eastbourne and offer both longer term placements for severely disabled looked after children and overnight short break packages for others meeting specialist service eligibility criteria. Both have been judged as outstanding in every area and are Autism Accredited

5.6.2 Jemini Response
Jemini Response describes it’s residential service as providing an individual care and education package for children and young people with Learning Disabilities and Challenging Behaviour, which is designed to meets their holistic needs within a small homely community based environment.

5.6.3 Mayfield children’s home
Mayfield Children’s Home is a privately owned home for children and young people with learning difficulties and associated challenging behaviour in Mayfield, East Sussex. Mayfield can accommodate children between the ages of five and nineteen and young people in transition between the ages of eighteen and twenty five.

5.6.4 Greenacres
Greenacres provide accommodation and support to five children between the ages of 9-16 years with learning disabilities, autism and or associated challenging needs.

In addition to this there are several independent agency homes in East Sussex whose population will include young people with SEN and BESD but whose services are not generally targeted towards disabled young people. These agency homes will most likely have a residential population drawn from other local authorities.

5.7 Equipment
National evidence suggests waiting lists for equipment can impact on independent mobility of children and on social and educational development, choice and clinical need. Until October 2011 equipment for both adults and children across social care and health was contracted to be provided, fitted, maintained and delivered by ICES, the Integrated Community Equipment Service.

Following national guidance, therapy services transferred to Kent Children’s Integrated Therapy and

Equipment service in April 2013, with equipment provision to move over by the end of the year. Interim changes to the equipment service revolve around the use of local providers which is not exampled elsewhere nationally. There are currently 22 providers of specialist equipment, 6 of whom are local suppliers, and all of whom are specialists for specific types of equipment. There is no preferred provider list and although there are a selected number of providers, this is not restricted. Between October 2011 and July 2013 there have been approximately 900 pieces of equipment provided in East Sussex, the greatest proportion of which were bath/toilet equipment (30%) and seating (21%). Compared to Q1 2012, most noticeably there has been a 3% increase in ramps provided in Q1 2013 and a 10% increase in seating. Conversely there have been 8% fewer hoists and 7% fewer standers provided (Figure 27).

In Q1 2013-14 compared to Q1 2012-13 there is a 10% increase in provision within Eastbourne, a 4% increase in Rother, Wealden has remained consistent, and a 7% fall in provision in Hastings and Lewes.

The 2013/14 budget for Equipment is £333,600, with an estimated income of £44,000, (compared to £72,000 in 2012/13). The use of recycled equipment in 2012-13 saved an estimated £60,100, with greatest savings for seating (£13,400), standing (£11,700) and bathing (£11,000) equipment (Figure 28).

There have been several advantages evidenced to date of using local suppliers: quick turn-around; flexibility; rapid removal and decontamination; ease of recycling and initial reports of increased family satisfaction with the service. Kent is looking to develop this local model when taking on
equipment provision for East Sussex.

5.8 Early years

Early years services for children with disabilities/complex special needs have recently integrated, incorporating:

- **The Early Years Teaching and Support Service (EYTSS)** work in partnership with parents and carers, foundation stage settings and other agencies to provide a specialist team of specialist early years practitioners, to provide early interventions for children with complex SEN and disabilities. As at April 2013, approximately 600 children were known to the Early Years Teaching Support Service and this is consistent with the number of children on the caseload at any one time over the last few years. Of this number, between 125 and 150 have complex needs and are part of the Early Support Programme. In 2012/13 statements were issued for approximately 155 children by the EYTSS.

- **The Early Years Communication Teams** are made up of Speech and Language Therapists and Therapy Assistants, Educational Psychologists, Early Years Specialist Teachers and Support Workers and operate an open referral system for children with complex and long term communication difficulties. As well as supporting pre-school children the team aims to work closely with parents and carers and provide services in the most appropriate and natural settings.

- **The East Sussex Early Support and Care Co-ordination Programme** was launched in 2005 with two designated Care Co-ordinators and other practitioners drawn from health, education and social care backgrounds undertaking the role of Key Workers. Aims are to clarify professional roles, reduce the number of times parents have to repeat information, increase level of information and family participation, have a named person as a keyworker, and reduce duplication and gaps in services. Of the 50 families responding to a 2009 evaluation of the service, 95% of those with a keyworker were satisfied or very satisfied with the service, and in particular valued: knowing the support was there; one focal person facilitating communication with multiple services; the additional information the keyworker provides; and help with arranging appointments. However, some families felt that while support was excellent it should have been provided at an earlier stage. As at April 2013, about 150 children were known to Early Support Programmes.

Schools may also choose to provide additional evidence based services over and above that which is part of local policy. For example if a school wanted to develop nurture classes then they may be able to access expert advice with the support of the local authority even though this is not policy based practice.

5.9 Keyworking

The overall aim of key working is to ensure the provision of holistic care and support to meet the individual needs of the child or young person with additional needs and their family. Keyworking is based on person centred, family focussed thinking and partnership working to coordinate an integrated package of support. Functions of keyworkers include: emotional and practical support; empowerment; coordination of services and practitioners; accessible point of contact; facilitating a single planning and joint assessment process; signposting; advocacy and facilitating integrated clinical and social care.

The Early Support Trust outlines three levels of provision:

- **moderate level of support**: key working support may only deliver a few of the functions for a limited time

- **high level of support** from a number of agencies: key working support at a higher level of intensity, but the intensity should quickly reduce. The key working practitioner could be any

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181 East Sussex Children’s Services (2013) Data, research and information team
182 East Sussex County Council (2013) EYTSS data
183 East Sussex Early Support and Care Co-ordination Scheme Annual Report 2008-09.
member of the team around the family and should be the one who is ‘best placed’ in terms of the needs of the family and the individual’s skills, capacity and relationships.

- **intensive level of support**, who require services from a number of agencies, including extensive specialist input, and complex packages of support: these families will probably have a statutory Education, Health and Care Plan and access to a personal budget.

Family Keywork is being developed across the East Sussex as a means of providing intensive support to families with multiple and complex problems, whilst making more cost effective use of total public sector funds.

5.10 Team around the family (TAF)
Where a multi agency response is required, Team around the family (TAF) brings together relevant practitioners with the family to address unmet needs. The members of the TAF work with families with children predominantly under the age of five, and often during a woman’s pregnancy working together to plan co-ordinated support from agencies to address problems in a holistic way through an agreed written support plan which clarifies each team member’s responsibilities. TAF includes: Health Visitors; Children’s Centre Keyworkers; Midwives; School Nurses and Nursery Nurses. The team decide what level of support is appropriate using the Continuum of Need. In 2012/13, the TAF process was piloted in the Bexhill area prior to being rolled out across the county and by September 2013 each of the nine early years clusters had TAF meetings in place.

5.11 Inclusion services
Inclusion Services cover a range of services through assessment to delivery for children with SEND and those children with less complex needs who are vulnerable to disaffection. The service comprises of 200 staff and an £8 million budget providing complex funding across and between services, of which the high needs budget is part of the national SEND reform programme.

5.11.1 Flexible learning educational support service (FLESS)
The Flexible learning educational support service (FLESS) is a team of teachers and teaching assistants who support schools in providing education for sick children, offering: attendance at all personal education plan (PEP) meetings in schools; teaching and support for sick children in small groups at locations around the county or at home; teaching and support in hospital children’s wards; online learning and initial help in reintegrating children back into school after periods of absence due to ill health. In the 2012/13 academic year 220 children were referred to FLESS, an increase of 32% on the previous academic year, and 370 Elective Home Education families accessed the service.

5.11.2 Anti-bullying service
The anti-bullying resources produced by East Sussex Anti-Bullying Team to support SEND children and young people who are experiencing bullying behaviour are being used to inform the development of national training resources which are being rolled out nationally to all Achievement for All schools. These resources are aimed at measurably reducing the impact and incidence of SEND bullying, ensuring school leaders feel informed and confident in addressing whole-school bullying and all school staff feel more confident safeguarding SEN/D pupils. It is expected that the Anti-Bullying Team will assist in the delivery of the training events regionally.

5.12 Childrens centres
There are currently 31 Children’s Centres across East Sussex offering a range of services, information and support to all families with children under five. In April 2012 18% of disabled children across East Sussex had been contacted by Children’s Centres. This compared to 13% in May 2011. In all but 6 Children’s Centre’s in the county this represented an improvement in establishing contact compared to the previous year.

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184 East Sussex County Council (2013) Inclusion Support Services
185 East Sussex County Council (2013) Anti-bullying co-ordinator
5.13 Childcare
A 2012 National Childcare Affordability report collected data from 124 local authorities in the UK and ranks East Sussex 45th out of 63 counties where 1 is most affordable and 63 is least affordable childcare. Of the average yearly earnings in the county, 21% is spent on childcare, higher than Kent, Surrey and west Sussex. The 2011 Parent Childcare Sufficiency survey found 22% of parents in the county were not satisfied with the level of available childcare, mainly due to cost of childcare, hours provided and type of childcare. Less than 1% reported childcare to be unsatisfactory specifically related to SEN.

5.14 Portage
Portage is a home-visiting educational service for pre-school children with additional support needs and their families. Currently there is no specified portage provision within East Sussex, although the services associated with portage are offered through the early years support programme.

5.15 Education
In 2012/13 financial year, against a DfE target of 95%, 93% of all first statements of SEN in East Sussex (excluding exception cases) were issued within 26 weeks, falling to 90% when including exception case (meeting DfE targets).

A 2012 Scrutiny review of school exclusions in East Sussex concluded that the high quality and availability of special school provision in the county is almost certainly creating a misperception amongst some school staff that special schools provide the best option for a wide range of less serious behavioural problems. This is reflected in national evidence suggesting schools sometimes identify cases of SEN when the real issue is poor pastoral support. Once established in a special school for any length of time it becomes difficult for parents to believe needs can be met in mainstream school, even after the behaviour issues have been addressed. While a school loses approximately £4,000 per year for a permanently excluded child, it typically costs £12,000 to educate a child outside mainstream provision, usually paid for by the Local Authority. The review concluded better information on what “behaviour support” and “SEN Support” in schools is required.

5.16 Transport
Policies around transport have recently been changing as part of the wider SEND reforms. Provision to accessible transport has changed to “travel assistance” which may provide personal transport budgets in place of physical transport depending on an individual’s circumstances. Through these current reforms travel assistance must now consider parent’s choice, both in terms of school and transport. Of the 58 families recruited to the SEND pathfinder programme, 11 are trialling personal transport budgets.

Where physical transport is provided, children are risk assessed to ensure transport provided meets their needs. Escorts are provided to supervise pupils on a vehicle and to assist with boarding and leaving the vehicle where the child has a severe physical condition, a medical condition requiring immediate treatment, or severe behavioural difficulties meaning the health and safety of the child, driver or anyone else travelling in the vehicle would be at risk. A transport compliance and safeguarding training package is currently being developed by the Council and will be offered to the ten main schools with transport provided relating to SEN (Table 18), with children with the most complex needs at Chailey Heritage. Of these 735 for whom transport is provided, over three quarters (77%) are male and 23% female.

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188 East Sussex County Council (2011) Childcare Sufficiency Assessment
189 East Sussex Children’s Services (2013) Data, research and information team
190 Children’s Services Scrutiny Committee (July 2012) Scrutiny review of school exclusions in East Sussex: Report by the project board
Table 18: The ten main schools home to school transport is provided for

<table>
<thead>
<tr>
<th>School</th>
<th>Type of needs</th>
<th>Number of children transported as at September 2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glyne Gap School/Nursery/FE</td>
<td>PD/ASD/SLD</td>
<td>110</td>
</tr>
<tr>
<td>South Downs CSS West+East</td>
<td>PD/ASD/SLD</td>
<td>88</td>
</tr>
<tr>
<td>Saxon Mount Secondary</td>
<td>ASD/MLD/SLCN</td>
<td>87</td>
</tr>
<tr>
<td>Hazel Court Secondary/FE</td>
<td>PD/ASD/SLD</td>
<td>80</td>
</tr>
<tr>
<td>Grove Park Primary/Secondary/FE</td>
<td>PD/ASD/SLD</td>
<td>68</td>
</tr>
<tr>
<td>Lindfield School</td>
<td>SPLD/MLD</td>
<td>64</td>
</tr>
<tr>
<td>Torfield School/Early Years Centre</td>
<td>ASD/MLD/SLCN</td>
<td>60</td>
</tr>
<tr>
<td>Cuckmere House Primary/Secondary/FLP/SAC</td>
<td>Behavioural issues</td>
<td>59</td>
</tr>
<tr>
<td>St Marys School, Horam</td>
<td>Behavioural issues</td>
<td>58</td>
</tr>
<tr>
<td>New Horizons School</td>
<td>Behavioural issues</td>
<td>42</td>
</tr>
<tr>
<td>Chailey Heritage School</td>
<td>Complex health needs</td>
<td>19</td>
</tr>
</tbody>
</table>

Source: ESCC Economy, Transport and Environment Team

Provisional information suggests that there are currently 1,000 Children with SEN who access home to school transport. Of this number 740 are male (74%) and 260 female (26%). For the schools listed above the September cost per school ranged from £3,900 to £41,200. The greatest numbers of children with SEN requiring home to school transport are in years 8 to 11 (aged 12 to 16) (Figure 29) which corresponds with the years with the greatest number of statements in 2013.¹⁹¹

Figure 29: Home to school transport for young people with SEN by academic year

Source: ESCC Economy, Transport and Environment Team

Where safely possible, transport will be provided for more than one student in one trip.¹⁹² In the majority of cases there is a phased transfer of transport for Year 6 to secondary school where transport is assessed and families are contacted letting them know they are eligible if they would like to opt in. It is then up to the family to opt in to the service. The provision of transport is as flexible as possible to meet need above and beyond that written in the statement if there is no additional cost implication to doing so.

A recent review of school transport has been conducted relating to the introduction of personal transport budgets in East Sussex

5.17 Transition

The East Sussex Transition Service became operational in 2011 to meet the visions set out in the

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¹⁹¹ East Sussex County Council (September 2013) Economy, Transport and Environment Team
¹⁹² East Sussex County Council (2012) School Transport for pupils with special educational needs.
2009 multi-agency transition strategy. The Transition Service has an ongoing caseload of approximately 300 children and young people that they review from the age of 14 years and support from the age of 16 years, and around 1,500 assessments are processed per year. East Sussex County Council received the highest national grading for the multi-agency transition process for meeting all statutory and guidance requirements, innovative practice, strong leadership and creative solutions, active strategic involvement and commitment to encompassing wider groups of vulnerable young people in future development. The Transition service has brought together professionals from a number of different disciplines and is regarded as having very good levels of interaction with young people encouraging their input into the process where possible. Whereas the previous assessments concentrated on what the young person was not able to do, the new assessment concentrates more on what a person’s abilities are and includes a person centred “this is me” section and input from Parents and services.

However, a recent review of the new Transition Service found there was still room for improvement in order to meet the needs of the local population, including:
- More robust strategic accountability/responsibility for transition, e.g. via the multi-agency forum
- Review current Transition Strategy, i.e. who would be considered vulnerable in transition
- Establish clear performance indicators/outcome monitoring to influence strategic planning
- Establish clearer links with ACS and other relevant partners
- There are barriers to establishing relationships with health, due to how health budgets are managed, how decisions are made, and balancing four panels for agreeing care packages.
- Schools have growing concerns about young people not meeting Transition Service criteria.

In addition to this, Sussex Partnership Trust’s Age and Healthcare Steering Group has identified that young people aged 16 to 17 are currently unable to access or receive appropriate services from acute services and that the organisation needs to be more flexible in supporting their needs, particularly through the transition to adult services. There is also no transition service for those with less complex disabilities and needs who are referred straight to Adult Social Care at 18, although there are targeted youth support services.

5.18 Self directed support and personal budgets
Self-Directed Support (SDS) provides social care to disabled children by giving disabled children and their families more opportunity to identify their own needs. It enables them to plan how to meet these needs with a Personal Budget, as opposed to a package of care organised by the County Council. SDS involves:
- Families identifying their own social care needs and personal aspirations and outcomes
- Eligible families being given an early indication of funding available to support their needs
- Young people and families (with appropriate help) developing a support plan of how needs and outcomes will be met
- Families (with help if required) deciding arrangement of services to meet needs, either via a Direct Payment, having services arranged by the Council or a mixture of both.

Personal budgets (PB) allow individuals entitled to social care funding to choose whether they take their budget as a Direct Payment or prefer a local authority officer to commission services for them, whilst choosing how and by whom their needs are met. From October 2013, disabled young people aged 16 – 25 will move onto the new benefit for disabled people, Personal Independence Payments (PIP). PIP will replace Disability Living Allowance (DLA) for ‘working age’ disabled people.

In February 2011, 18 families were involved in a Personal Budget Pilot within child social care in East Sussex in Q2 of 2013/14, 9 children and young people had a personal budget at a total quarterly cost of £18,300. Initially personal budgets were piloted with existing services, but are now being rolled

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193 East Sussex County Council (April 2013) Joint Commissioning for Children and Young People with SEN and Disability
194 K&K Associate Consulting Ltd (March 2013) Report on the evaluation of East Sussex County Council’s Transition Service
197 East Sussex County Council (2013) Adult Social Care
out across the county to new families. As part of the Individual Budgets pilot scheme, a comprehensive list of services and support for children and young people with disabilities and complex health needs in East Sussex can be found at: 

Interim evaluation of the Personal Budgets Pilot in East Sussex[^198] found the resource allocation system (RAS) provides a more equitable and fair system which allows children with similar levels of need, in similar circumstances, to be guaranteed the same outcomes. The evaluation also demonstrated that the development of support plans is simpler when budget and resources are known from the start and there are benefits to families when they are enabled to determine how budgets are spent to best meet their own needs.

Personal budgets do not include NHS health funding (see 5.4.3.) unless care or support is jointly funded (e.g. under Section 75). However, as outlined previously, personal healthcare budgets are being piloted in a number of health care trusts nationally, including East Sussex[^199].

Direct payments (DPs) are cash provided by a local authority in lieu of a service. In Q2 2013/14 113 children and young people received a DP package at a total quarterly cost of £208,300, compared to 132 children with DPs in Q1 2013/14 at a cost of £194,600.[^200]

As an example of how personal budgets have the potential to be used locally, an initiative is currently being developed to look at how the direct payment and personal health budget system can support four 19 to 25 year olds at Chailey Heritage who want to access independent living together. The initiative is also exploring the potential for learning and vocational options for young adults with profound disabilities. This may involve sharing elements of care by pooling budgets, for example therapy and activities, and requires close joint working between, amongst others, the Local Authority, (Adult Social Care & Children's Services), Continuing Health Care, housing associations and the four families and young people. If this is found to be feasible the aim would be to investigate how this way of supporting young adults could be built into the SEND care pathways in the future for some young adults with EHCs to support them to determine and manage their own future.

National evidence of effectiveness and best practice of the personalisation approach to service provision can be found in the appendices, available on request.

5.19 Vulnerable children
5.19.1 The THRIVE programme

THRIVE is a three year programme which aims to reduce demand for high cost statutory social care services and reduce East Sussex County Council referrals, child protection plans and looked after children (LAC) by investing in early help services, targeting services towards the most vulnerable families, helping them to build resilience and coping strategies so that families can stay together and enjoy better outcomes where it is safe to do so. Where it is not, intervention will be as early as possible to secure good permanent alternatives for children. Compared to statistical neighbours and South East local authorities, overall rate of referrals, Child protection plans and assessments are high, although the inception of THRIVE has meant significant reductions in each of these.[^201]

5.19.2 Looked after children

Disabled children are one of the most vulnerable groups in relation to neglect and abuse. Safeguarding referrals for children with disabilities has increased over recent years (Figure 30) and so

[^199]: East Sussex County Council (2011) Your questions answered An introduction to Children and Young Peoples’ Personal Budgets
[^200]: East Sussex County Council (2013) Children’s Services Performance Monitoring
[^201]: East Sussex County Council (2013) Children’s Services Portfolio Plan 2013/14 – 2015/16
there is a rising demand for placement outside the family.\textsuperscript{202} Between March 2011 and March 2012 the number of placements of disabled LAC young people continued to rise from 46 to 51. Between 2011/12 and 2012/13 Agency Foster care referrals decreased from 37% to 29% of referrals, while ESCC Foster care referrals rose from 13% to 29%.\textsuperscript{203}

![Figure 30: Number of placements due to safeguarding referrals 2007/08 to 2010/11](source: East Sussex County Council 2012)

Placements due to safeguarding referrals rose by 140% between 2007/08 and 2010/11 (from 10 to 24) (figure 31), while placements due to family breakdown referrals decreased between 2010/11 and 2011/12.\textsuperscript{204}

![Figure 31: placements of disabled LAC by referral type 2007/08 to 2011/12](source: East Sussex County Council 2012)

### 5.20 Short breaks

Short breaks allow disabled children and young people, aged up to 19 years, the opportunity to spend time away from their families, and can involve a few hours or a few days, weekends, weeklong breaks or holiday activities at home or in a carers home, in the community or in a residential setting. There are three types of short break service:

1. **Universal services** – aimed at those at a lower rate of disability living allowance (DLA) or who receive SAP at school. However, all disabled children should have access to these services.

2. **Targeted services** – aimed at those receiving middle or higher rate DLA, who have a statement of SEN, attend a special school, have a placement at a special facility, receive early years support or are supported by the Inclusion Bursary Fund.

3. **Specialist services** – for those with a severe learning or physical disability or complex health need, who meet Child Disability Service criteria and need a high level of service.

Commissioning of short breaks is underpinned by the East Sussex County Council Short breaks Services Statement\textsuperscript{205}, developed in consultation with families, carers, and providers. This statement ensures the range of short breaks “bought and provided” are those valued by and needed by families.

In 2012/13 there were 755 children accessing short break services,\textsuperscript{206} a rise of 2.5% from 736 children.

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\textsuperscript{202} East Sussex County Council (2012) DRAFT Children’s Services Portfolio Plan 2012/13 – 2014/15

\textsuperscript{203} East Sussex County Council (2013) Children’s Services Portfolio Plan 2013/14 – 2015/16

\textsuperscript{204} East Sussex County Council (2012) DRAFT Children’s Services Portfolio Plan 2012/13 – 2014/15

\textsuperscript{205} http://www.eastsussex.gov.uk/NR/rdonlyres/20388369-A816-418C-8685-0BA0D3AD2ECA/0/short_breaks_services_statement.pdf

\textsuperscript{206} East Sussex county Council (2013) Short Breaks Annual report 2012/13
The greatest numbers of children and hours of short breaks accessed were in Quarter 2 and the fewest children and hours in Quarter 4. This reflects seasonal variation in the demand for short breaks, and echoes the pattern of all service industries nationwide. Just over 65% of all short breaks accessed in 2012/13 were provided by residential centres or After School clubs and holiday play schemes (ASCHPS) with 15% provided by SCOPE and the outreach service (table 25). The remaining 20% of services are targeted towards children with more complex needs that can’t be addressed by general short break provision.

Feedback on service provision is collected on a service-by-service basis and any issues such as waiting lists or issues with individual children are dealt with at regular meetings between East Sussex County Council and local services. Whilst this means that issues are dealt with on a regular basis there is no collation of feedback on short breaks services which would be a valuable resource for directing short breaks services to more efficiently meet need.

The Short Breaks Grant Scheme which was introduced in 2012/13 and supports local organisations with grant funding to deliver short breaks: £107,600 has been allocated to ten projects to date including after school and holiday clubs, adaptations to buildings to enable accessibility, visual arts, music and dance lessons and workshops, sporting equipment, residential short breaks and staff training. Providing support to families of children with autism was an identified priority throughout 2012/13 and 266 grants of £300 each (£79,800 in total) were awarded to eligible families of children with ASD for equipment or short breaks.

5.21 Leisure services
A 2013 short break sufficiency study aimed to identify how short break funded activity fits into leisure, art and sport activity available for children and young people with disabilities across East Sussex. This study identified 42 sports activities accessible for children and young people with disabilities, 102 arts activities and 386 leisure activities, including play schemes. Of this number 2 sports activities are funded by short breaks, 4 arts activities and 362 (98% of short break funding) leisure activities.

5.21.1 i-go card
Launched in July 2013, i-go is the passport to leisure activities for children and young people with disabilities and special needs in East Sussex and is run by Rockinghorse Children’s Charity and Information for Families at East Sussex County Council with funding from the Big Lottery Funding. Early data from the 75 families who were part of the pilot and have requested the i-go card since July 2013 shows that just over 70% of those with i-go cards are female, and just under 30% male. Of those with cards to date, 10% are aged under 4 years, nearly one third are aged between 5 and 7 years (32%), a quarter between 8 and 10 years, 17% aged 11 to 13 years and 15% aged 14 years and above.

5.22 Obesity
The National Child Measurement Programme (NCMP) measures the weight and height of children in reception class (aged 4 to 5 years) and year 6 (aged 10 to 11 years) to assess trends of overweight and obesity levels within primary schools. Nationally, schools are encouraged to record SEN and disabilities alongside the NCMP but East Sussex does not include this information in the measurement programme.

5.23 Housing
The disabled facilities grant (DFG) is a statutory requirement and is a district and borough council held grant to cover the cost of adaptations, up to £30,000, to facilitate the child to be cared for at home. DFG is not means tested for children. Between 2011 and 2013, 37 children and young people in East Sussex received DFG, 22 in 2011/12 and 15 in 2012/13. The most common reasons for DFG

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207 East Sussex county Council (2012) Short Breaks Annual report 2011/12
208 East Sussex county Council (2013) Short Breaks Annual report 2012/13
209 The Institute of Chartered Accountants in England and Wales (2013)
210 East Sussex County Council (2013) Short breaks Sufficiency Study
are bathroom adaptations and access adaptations. In addition to the £30,000 contribution from district and borough councils, East Sussex County Council (ESCC) provided £121,000 top-up funding in 2011-12 for 9 adaptations and in 2012/13 £53,000 for 2 adaptations. The majority of adaptations fall within the £30,000 threshold.\textsuperscript{211}

5.24 Information and advice
5.24.1 The Local Offer
When the Children and Families Bill becomes enacted in 2014 local authorities will be required to publish and keep under review information about services they expect to be available for children and young people with special educational needs aged 0 to 25: the “Local Offer”. The intention of the local offer is to improve choice and transparency for families, to enable professionals to understand the range of services and provision in the area, and to inform commissioning. The local offer will be developed jointly by parent carers, young people and professionals and will cover: education, health and care provision; arrangements for identifying and assessing children and young people with SEN, including EHC assessments; other educational provision; training provision including apprenticeships; school travel; support moving between different phases of education and preparing for adulthood; sources of information, advice and support; and complaints procedures.

The Local Offer is a new way of working and a new approach to delivering information. The Local Offer can only be delivered by working in true partnership with parents and young people, and with a shift in culture to one of transparency, clarity of information and a willingness to work in a different way. This approach will mean:

- Improved outcomes for children and young people – more information easily available to help make better choices. Information will be ‘pushed’ to parents/young people to tell them about services/support they previously would not have known about.
- Parents and young people will feel informed and empowered to make choices.
- Expectations will be managed – people will be clearer about what is available and why, and what alternatives are available.
- More effective signposting – less disappointment for families who have been incorrectly referred to services in the past.
- The relationship will change between parents/young people and professionals as there will be more honesty, better accuracy of advice given, less time wasting and more trust.\textsuperscript{212}

The SE7 partners jointly developed a ‘framework’ for The Local Offer to ensure that the type of information published would be similar across the seven authorities. Parent Information Contacts (PICs) will become information champions to help families and those who work with them access information and will be vital partners in keeping the information up to date and in reaching more families in the community. During 2012/13 12 new Parent Information Contacts (PICs) were trained and there are PICs in over 50% of schools, Children’s Centres and Libraries.

5.24.2 Information for families (IFF)
Information for families (IFF) provides information and support to parents/carers of children with additional needs or disabilities. The 2012/13 budget was £377,000 across East Sussex County Council (£217,000), Early Intervention (£128,000), Short Breaks (£26,000), Participation (£4,000) and Miscellaneous (£2,000).

In 2012/13 there was an average of 579 contact centre calls a month to the IFF, a slight decrease of 2% on the previous year. Level 1 (continuum of need) contacts (e.g. childcare queries) fell by 25% between 2011/12 and 2012/13, while Level 2 (advice needed usually SEND) and Level 3 contacts (High level needs) fell by 17%, but it is unknown whether this decrease is related to recording and publication changes in this period of change. Of the total calls to IFF specifically relating to SEND:

- Approximately 300 families of children with SEN contacted the IFF due to difficulty working with schools resulting in loss of trust, frustration and disputes.

\textsuperscript{211}East Sussex County Council (2013) SEN and Disability Development Manager
\textsuperscript{212}Hampshire County Council (Dec 2013) Appendix 1 – SE7 ‘Local Offer – not a Directory’ Document
• About 30 families contacted the IFF due to their child being excluded from school trips because of behaviour or medical needs
• Approximately 100 families experiencing informal or illegal exclusions.

Q1 2013 information shows that, of those needing personalised advice, the most common types of child additional needs were: ASD (often EBSD or mental health); Learning difficulties e.g. Dyslexia, Dyspraxia, global delay (often with EBSD or mental health); Speech, Language and Communication Needs (often with EBSD or mental health); Behavioural, Emotional and Social Difficulties; Medical Conditions; Mental Health issues (anxiety) and Physical Disabilities.

5.24.3 Additional resources
• ESCIS - East Sussex Community Information Service is a computer database of local and community information developed and managed by the Library and Information Services of East Sussex County Council in association with Brighton and Hove Library Service. ESCIS holds information about 7659 organisations based in East Sussex and Brighton and Hove
• 1space - East Sussex County Council developed the directory www.eastsussex1space.co.uk to make it easier for people find care, support and wellbeing services by bringing together groups and organisations offering services for people of all ages and a diversity of needs, into one place online.

5.25 SUMMARY OF SERVICES IN RELATION TO NEED

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<th>Area</th>
<th>Key Findings</th>
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| Children's Disability Service | - The Children's Disability Service (CDS) currently supports 275 children and young people with disabilities: 150 by the Disability Duty Team; and 125 by the Family Support Team and Looked After Children Service.  
- Over half (52%) referrals to CDS in 2012/13 were not accepted.  
- Nearly two thirds (64%) of all those referred to CDS are Children in Need. |
| Types of SEN and disability  | - Nurture classes piloted in primary schools indicate marked improvement in self-esteem, observed pro-social behaviour, communication skills and understanding of language.  
- SEN agency placements for moderate learning difficulties have increased 114% over the last year.  
- Those with milder needs or emotional or behavioural difficulties often don’t meet eligibility criteria for services so there is a gap in support. |
| Education                 | - In many schools the provision of educational support for SEN is not underpinned by a culture of inclusiveness.  
- There are inequalities in level of provision for pupils with behaviour related SEN compared to that provided for pupils with physical disabilities. |
| Health                    | - Maternity and paediatric services in East Sussex are currently undergoing restructure in order to fully meet national standards of care.  
- The work of the Well Child Nurse has effectively developed cost-effective provision of local care packages to support children at home as an alternative to tertiary placements.  
- There are high numbers of referrals to some services which do not result in the service being provided. Notably for therapy services and the Children’s Disability Service.  
- There are a number of ongoing issues being addressed with Children’s Integrated Therapy Service including: inconsistent information coding; and a lack of access to suitable clinical space to provide efficient access to therapy services.  
- Demand for equipment is increasing. |
| Short Breaks and Leisure  | - The numbers of children accessing short break services increased 2.5% between 2011/12 and 2012/13 (736 to 755).  
- Preliminary data indicates that girls, and those with communication needs are more likely to take up the i-go leisure card. |
| Other findings            | - East Sussex County Council received the highest national grading for the multi-agency transition process.  
- Evidence indicates that there will be increasing pressure on Transition Services.  
- A new local model for equipment provision shows faster turnaround, greater flexibility, greater use of recycling and decontamination of equipment and initial reports of increased family service satisfaction.  
- Safeguarding referrals for children with SEN are increasing, resulting in rising demand for placement outside the family.  
- East Sussex anti-bullying resources, produced to support SEND children and young people, were used to inform the development of national training resources which are being rolled out to all Achievement for All schools in the country. |
The National Service Framework for Children, Young People and Maternity Services, Standard 8 outlines the main issues of importance reported by children and young people with disabilities.

Disabled children want to:
- Be listened to when decisions are made about their lives;
- Have friends of the same age or who share similar experiences;
- Do the same things as other children and young people of their age – shopping, going to a cinema, clubbing, going to youth and sport clubs, playing football etc;
- Have the opportunity to be involved in out-of-school activities;
- Be safe from harassment and bullying;
- Have control of spending money, and have enough money to enjoy life; and
- Live in a society where they don’t face prejudice.

Service delivery
A consultation event by the East Sussex ‘Families with Multiple Problems’ project looked at families requiring significant intervention from a range of services and, amongst other things, found that:
- One person co-ordinating a family’s support in the longer term with all members of the family is working
- Services can exacerbate problems by not listening to, and therefore disengaging families
- There remains a lack of communication between different services
- Services sometimes make decisions on behalf of families that are not what the family wants
- Families want plans that focus on changes and how to achieve them
- Fewer services working effectively together are much more helpful than lots of services working ineffectually.

Priorities outlined in the 2010/13 East Sussex Participation Strategy echo the voices of parents to:
- Improve information collection and sharing knowledge
- Evaluate and demonstrate impact and ensure feedback to participants

• Ensure decision-making is better informed by the views of children, young people, parents and carers
• Develop skills and knowledge
• Pro-actively work with minority, underrepresented, marginalised and vulnerable groups

**East Sussex SEND pathfinder**
Initial feedback from the 70 families involved in the piloting of plans in East Sussex has indicated the value of being directly involved in contributing to the plan, the fact that there is just one place where the information is held, and the multi-agency involvement in the development of the plan.

**Inclusion**
Between April and June 2012 the SEND pathfinder board commissioned research looking at the views of 120 children and young people aged 8 to 30 on issues of inclusion. The key issues identified were

1. **Attitude, behaviour and understanding of disability** to be addressed across school staff and peers to enable inclusion by tackling bullying, equipping teachers to respond to inappropriate comments, and enabling social spaces for students to interact together.
2. For some young people **loud noises and crowded spaces** make inclusion very difficult
3. **Access to public transport, taxis and school trips** can be difficult, particularly for young people using wheelchairs, but also financially. An accessible coach would be beneficial for school trips, as would safety training for those driving public transport and financial consideration.
4. **Access to activities, places and equipment** is problematic, particularly in relation to space and building layout for many pubs, and some leisure spaces, e.g. where the toilet is upstairs. Issues such as the need for more audio books in libraries, more inflatable swimming chairs and more accessible equipment in parks were also raised.
5. **More involvement in decisions** is wanted, for example school councils should have a dedicated space for a disabled young person, and more disabled young people should be involved in local design e.g. parks.
6. **Activities need to be made more affordable**, particularly if an accompanying carer is needed
7. **Information about activities should be more accessible** as nearly all primary school children didn’t know what a youth club was or where they were – this could be promoted through schools.
8. **Reduce repetitiveness and complexity of filling out forms** e.g. for housing and disability benefits

**Accessibility and participation**
Access to positive and inclusive activities improves disabled children’s health and wellbeing. Disabled children and their families want to benefit from the experiences of trained staff and want more choice, support to pursue individual interests and the opportunity to make new friends. Disabled children and their families reported improvements in participation of equal importance as improving access and stressed the importance of their involvement in decision making about services offered.

In a 2009/11 government survey, parents identified the attitudes of others as being one of the most significant modifiable barriers encountered by their children along with a lack of help or assistance (figure 32).

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216 East Sussex County Council (July 2012) SEND Pathfinder Consultation: report of the views and ideas expressed by children and young people on issues of inclusion.
217 C4EO (2009) Disability Directors’ summary 2: Sept 2009 Centre for Excellence and Outcomes in Children and Young People’s Services
Figure 32: Barriers to participation experienced by children aged 11-15 in Great Britain, 2009/11

**Source:** Life Opportunities Survey, Wave one results, 2009/11

**Figure Text:**

### and prejudice

In the Bullying local 2013 Safer Schools survey of 10,500 students, the most common reason given for bullying was ‘your appearance’ (45%), followed by ‘how you act or your personality’ (40%). Fifteen percent of students cited a medical condition, disability or SEN as the reason they were bullied. However, when taken as a whole, prejudiced based bullying (e.g. bullying due to race, religion, sexual orientation, physical appearance, special educational needs or disability), was mentioned by two-thirds of those who reported being bullied (66%), a significant increase of 18 per cent on the previous year.

Young Inspectors’ were commissioned by the SEND pathfinder board to consult with children and young people about issues of inclusion, a key theme that emerged was the effect being bullied had on inclusion and a lack of belief that teachers were generally equipped to deal with these situations. In general, children and young people in East Sussex report a greater prevalence of bullying (66%) and physical bullying (43%) than nationally (52% and 29% respectively).

### ASD assessment and diagnosis

A review of parents’/carers’ views of ASD assessment and diagnosis indicated that families wanted: improved communication, although the keyworker was valued in aiding communication across services; knowledge of the support available; a more efficient process with choice of appointments and all parties accessing relevant reports and documents before meetings; Speedier confirmation of diagnosis to enable application for necessary benefits; Communication skills to be incorporated into practitioner training.

### Early years interventions

National research suggests that in early years interventions parents most value: key-workers; web based information; high quality pre-school centres, particularly for most disadvantaged children to improve cognitive development and reduce need for SEN at primary school; support at time of diagnosis; Evidence of achievements and developmental milestones; opportunities to develop parent skills; joined up and coordinated services; enabling of parents to enter or return to work; assessments considering whole family needs.

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218 Safer Schools Survey (2013) Anti-bullying Team
222 C4EO (2009) DISABILITY: Progress map summary. June 2009. Improving the well-being of disabled children (up to age 8) and their families through increasing the quality and range of early years interventions. Centre for Excellence and Outcomes in Children and Young People’s Services
Childcare provision
National research indicates that parents feel there are numerous gaps and barriers to childcare for disabled children. Specialised childcare tailored to a child’s specific needs was a significant issue for parents, as well as: inclusive care for both disabled and non-disabled siblings; emotional and practical support for parent carers; accessibility of care for children of asylum seekers; childcare workers who are also parents of disabled children; appropriate services for children as they get older; and transition care from child to adult services. Three of the most frequently cited challenges relating to childcare for children with disabilities are: poverty and childcare costs; lack of appropriate places and service, and inadequate information. 

Research in Hertfordshire found that some parents from BME groups report that cultural factors need consideration in some aspects of service provision, for example food available at play schemes may not be appropriate for all cultures.

Children’s centres
A 2011 snapshot of 1,800 families attending children’s centres in East Sussex showed that 96% of respondents were satisfied with the services they had received from Children’s Centres and 78% reported that things had changed for the better as a result of contact with the Centre. Three percent of respondents had a child with additional needs under the age of 5 years. The survey also shows that 58% of attendees were from a target group and 72% were either from a target group or lived in a 30% most deprived SOA. These results indicate that Centres are broadly successful in building positive relationships with families when they attend and that the targeting of services is developing.

Transition
An independent evaluation of the East Sussex Transition Service 18 months into its existence involving parent carers, schools and the Transition Service indentified that the service to date is well regarded by providers and service users alike. Although it is early days and the sample was small, parent carers reported that on a scale of 1 to 10 they were 8.3 satisfied with the Transition Service and that the key worker approach is particularly valued. Importantly, the perception of feeling at a “cliff edge” at aged 18 to 19 has diminished due to the clarity of pathways since the Transition Service began, and the fact that the Transition Service are working with young people from an earlier age and having conversations with children and their families much earlier about life options and choices. However, there is anxiety that the level of support received from the Transition Service would reduce in the future, and observations that funding decisions should be made more in advance of the start of the academic year to give families time to make arrangements if necessary.

Child and adolescent mental health service (CAMHS)
Service user experience of CAMHS services is collected via customer postcards. Of the postcards submitted in 2012/13, East Sussex achieved some of the highest satisfaction scores relating to service provision across Sussex (Figure 33). However, when asked whether service users felt involved in decisions about their care, 76% of East Sussex respondents responded positively compared to 79% across Sussex and 85% in West Sussex (Brighton and Hove had no respondents for this question).

227 K&K Associate Consulting Limited (2013) Report on the evaluation of East Sussex County Council’s Transition Service
A 2012 project allowed children and young people and their parents to reflect on their CAMHS and caring experience via a number of different outdoor activities. Key messages from parents included: a lack of understanding of how content of therapy sessions relates to behaviours encountered at home; the value of peer support and shared experiences for carers (with suggestions of opening the STOP programme beyond ADHD); that parents feel isolated and stop taking their children out as they struggle with behaviours and feel judged by others; and that their child does not have enough opportunity to socialise and have fun. Children and young people echoed that they also feel isolated, are often bullied in the school setting, and can be labelled as naughty within the school setting due to a lack of understanding about their behaviours. They would like to be able to express how they feel in creative ways rather than just talking, and find talking to others with similar experiences helpful.

**Chailey Heritage**

Preliminary insight from the Chailey Heritage School (CHS) and Chailey Heritage Clinical Services (CHCS) annual parental questionnaire 2013 indicates that parents have expressed high levels of satisfaction with all areas of joint working between CHS and CHCS, with 80% of CHS and CHCS staff agreeing that the integrated working between education, residential and clinical support to pupils in particular is improving.

**Personalisation**

An interim update report on the local personal budget pilot found that parents were initially concerned that introducing personal budgets was a way of cutting back on services, however, balanced with this was the prospect of increased flexibility, choice and control. As it is early days for personal budgets within SEND services feedback has been limited, but what has been gleaned so far suggests that having increased choice and control has had a positive impact for disabled children and their families as a whole. Of particular note was the fact that families tended to opt for personal assistants in favour of specialist services.

**Transport**

Consultation with those using home to school transport is currently underway with regards to understanding what is and is not working well in order to effectively target and increase the uptake.

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228 Sussex Partnership NHS Foundation Trust (2012) CAMHS Earthwise- LGF update
229 Chailey Heritage Clinical Services (2013)
of personal transport budgets (PTBs). However, SEND pathfinder consultation indicates that physical access is central to feelings of inclusion and currently there is no accessible 52 seater coach in East Sussex which means that disabled children and young people need to travel separately to their peers to attend school trips. Transport for carers if needed is also noted as additional expense.231

Leisure
An inspection of several local leisure facilities by a small group of young people with disabilities, learning needs and impairments found that some leisure provision remains inaccessible for young people with physical impairments, for example heavy doors, steps, inaccessible bathrooms and a lack of signage. However, the group found the leisure services inspected to generally be welcoming with friendly staff.232

Information and communication
Improved communication and provision of up to date information for parents and children with additional needs is a key theme across local surveys and consultations, with little strategy in place to involve young people in decision making relating to service design and delivery.233 Those involved in the Young Inspectors Programme see this as a way of involving and empowering young people.234 Parents and carers feedback also shows a desire for greater involvement, consultation and participation.235, 236

Families and carers
A local survey of the impact of caring on health and wellbeing identified that 89% of carers felt more stressed because of their caring role, 45% have suffered depression because of their caring role and 79% felt more anxious because of their caring role.237 This mirrors national evidence of the impact of caring on the mental health and wellbeing of carers.

East Sussex parent and carers perspectives of need
During this needs assessment, the Parent and Carer Council asked parents and carers of children with SEN and/or disabilities in the county who were members of the Council for their perceptions of services for their children. Responses were limited and were from families of children with more complex needs. The Issues raised included:

- Early Intervention: time between visits is too long when complex 1:1 development is needed
- A register of nursing support would be really useful for those on personal health budgets
- There is perception that the introduction of direct payments absolves the LA of responsibility
- There is a gap in provision of SALT/OT services for young children.
- Level of care needed for travelling means some pre-school nursery support is not accessible
- The inability to keep some children needing significant support within the local area significantly affects family well being and quality of time spent together
- Support is geared towards mothers and is lacking where fathers are primary carers, or for separated parents who continue to provide care for their children.

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232 Viewpoint data from Inspection of Youth Offending Work, 2011
235 Feedback from Changing Times event (2012) FIS/Parentlink
236 Information for families’ final report (2011) FIS/Parentlink
237 Care for the Carers (2013) Carers Week Survey
<table>
<thead>
<tr>
<th>Area</th>
<th>Key Findings</th>
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| Service Design and Delivery | - The key worker role is very highly regarded for in-depth knowledge of the child and their needs, and as single point of contact for parents and services, creating more efficient communication and less duplication.  
- There is a lack of communication between different services.  
- Inclusion of parent’s expertise in service design and delivery has been improving and families involved in the SEND pathfinder value their involvement in the development of the care plan.  
- There remains a paucity of parent/carer/young person feedback within and across services. |
| Service Provision  | - Parent carer perception is that support is lacking for fathers, particularly those who are separated parents.  
- Early feedback on personal budgets suggests that increased choice and control has had a positive impact on disabled children and their families as a whole.  
- It is felt that confirmation of diagnosis could often be quicker which would enable application for necessary benefits. |
| Inclusion and support | - There is a need for accessible transport to allow disabled young people to go on school trips with their peers rather than travelling separately.  
- A lack of knowledge about SEND within schools can lead to bullying and there is a lack of confidence that teachers are generally equipped to deal with bullying related to disability.  
- Peer support and experience is particularly valued by young people and their families. |
| Accessibility      | - Barriers preventing access to childcare include: cost, lack of appropriate services and inadequate information.  
- Building layout and design of public places and services can limit accessibility.  
- Some activities are not affordable, particularly when a carer needs to be paid for too.  
- Attitudes of others and a lack of help or assistance are the most significant modifiable barriers to accessing services. |
| Information        | - Improved communication and provision of up to date information for parents and children with additional needs is a key theme across local surveys and consultations. |
Semi-structured interviews have been conducted with key organisations and service providers to complement existing data for this needs assessment. In total there were 21 interviews conducted, of an average of 1 to 1.5 hours, with commissioners, providers and parent and carer representatives, including: SEND reform Implementation team; Children’s Social Care; East Sussex Healthcare NHS Trust; East Sussex Children’s Disabilities Services; Education Services; The East Sussex Parent and Carers Council and Family Information and Support Services. Issues below are those which supported local/national evidence or which were raised by multiple service providers as areas to note. A full table of service provider views is available on request.

**Currently working well in service provision**

- The new local model of equipment provision has improved service efficiency and delivery and developed national interest from other areas
- There are better relationships between families and professionals due to new, child-centred approaches to working
- The key worker role is very highly regarded for their in-depth knowledge of the child and their needs, and as single point of contact for parents and services meaning more efficient communication and less duplication
- The choice, range and flexibility of services being offered is highly valued by families and those referring them.
- There is a multi-agency perception that Personal budgets could begin to address family’s anxiety about accessing the support they feel is needed.

**Currently provided but could be improved**

- Work is still needed to change practitioner and family mindset to a new child-centred, outcome-based way of working - there remains silo working as services are not yet speaking a common language, even within services.
- There is a perception across providers that the recent change of therapies provider has resulted in a (temporary) loss of clear communication channels between agencies.
- There is a nationally recognised gap in how information and data on child disability is gathered and held but a new Child Health recording System (System1) is being developed and piloted in the county to address this gap.
- It is important to ensure that written information for carers (The Local Offer) is easy to follow and understand
- Changes to the social care transition service needs to be monitored because an increasing caseload as the team become established means need for resources will also increase. Several service providers identified that those needing support through the transition to Adult services will increase in coming years.
- Additional support is needed to engage children and young people in the process of developing their support plan
- Health and Social care services have different eligibility criteria, so when health care may stop social care continues which (unnecessarily) complicates the delivery of support to a young person.

**Gaps or issues with provision**

- The involvement of young people in the SEND reforms needs to be improved
- There needs to be greater clarity in the roles of different agencies in the care for children and young people with disabilities so that all services are more aware of their boundaries
- The culture within some schools needs to change to a different, more inclusive way of providing educational support. Best practice is needed for this.
- There is limited generic universal support across all schools for SEN, and while some provision is excellent, lots more is needed across the board.
- There are not enough alternative local residential placements for children who are unable to remain with their families
- Services are generally not successful at supporting fathers who are either living away or separated.
• Service providers, young people and families have all identified the need for an accessible coach in the county so that young people with SEN/D can travel to school trips with their peers rather than separately
• There is a nationally recognised gap in specialist nursing skills and community consultants for children with disabilities and this is reflected and currently being looked into in East Sussex.
• There is an apparent consensus that while CAMHS can provide emotional support for those aged over 11 years, there is inequitable provision for younger children.
• Funding is not always agreed in a timely manner and is something which can place a great burden of anxiety on families.

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<thead>
<tr>
<th>Groups of children or types of disability with specific needs</th>
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<tr>
<td>• Exclusion in primary school for SEN pupils has increased significantly in recent years and is a growing problem</td>
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<td>• A large number of young people accessing short breaks are autistic. Services delivery needs to be mindful of this</td>
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<td>• Short break support for milder disabilities is limited with access mainly through after school clubs and school activities.</td>
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<td>• Small babies are surviving longer and currently services do not take the long term view of support these babies will need. This will become more challenging to health and social care and eventually SEN provision.</td>
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<tr>
<td>• Those with mild learning disabilities or emotional or behavioural difficulties often do not meet criteria for services so may be falling through the gaps of support despite their vulnerability.</td>
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<td>• Children with ASD need greater support provision than currently received, particularly for mental health services and behavioural support at school</td>
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<td>• There is a general perception that there is a gap in support for 16 and 18 year olds due to the differing ending times of services. This is a nationally recognised issue</td>
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### OVERALL SUMMARY OF MAIN FINDINGS (LOCAL EVIDENCE UNLESS STATED)

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<th>Information</th>
<th>Key Facts and Issues</th>
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| **Local Population Demography** | - East Sussex has an older population than nationally and regionally, with no expected rise in the number of disabled children, yet complexity of need and demand on service is increasing.  
- The rate of young people with Learning Difficulties in East Sussex is rising out of proportion to both regional and national rates.  
- The number of young people with disabilities and long term illnesses claiming DLA is rising in East Sussex, yet remains half that at national and county level.  
- The number of girls claiming DLA locally is increasing nearly twice as fast as boys, yet there are still two and a half times as many boys as girl claiming DLA.  
- The rate of young people with moderate and severe Learning Difficulties appears to be rising out of proportion with regional and national figures yet is still significantly lower.  
- There has been a continuing year on year upward trend for pupils with SEN provision for Autism Spectrum Disorder (ASD), visual impairments (VI), profound and multiple learning difficulties (PMLD) and Speech Language and Communication Needs (SPCN). |
| **Information, Inclusion and Support** | - There is no commonly shared definition of disability used across services and therefore no consistent inclusion criteria for disability recording, particularly across health care systems.  
- There is a paucity of parent/carer/young person feedback in some services and little evidence of regular collation of service user feedback to inform provision across a whole service.  
- There is little strategy in place to involve young people in service design and delivery decisions.  
- Current inclusion of parent’s expertise in service design and delivery could be improved.  
- Parent carers report that there is a lack of understanding and acceptance of disability within the wider community. |
| **Poverty** | - There appears to be a relatively strong correlation between the distribution of pupils with SEN and the areas of the county within the most deprived 40% of LSOAs in England. |
| **Education** | - Against declining national trends, the number of the school population with statements has increased over the last five years.  
- Exclusions could be avoided if high excluding schools took responsibility for managing a wider range of behaviours.  
- While schools made adequate provision for pupils with physical disabilities, there is not comparable level of provision for pupils with behaviour related SEN.  
- Contrary to national trends, KS1 attainment of SEN pupils has fallen in East Sussex in Reading, Writing and Maths. |
| **NEET** | Over two fifths of SEN NEET young people (41%) have emotional or behavioural difficulties, and 1 in 5 have moderate learning difficulties, representing a 4% increase for emotional or behavioural difficulties, and a 1.8% increase for specific learning difficulties from 2012. |
| **Placements** | The numbers of safeguarding referrals for children with disabilities has increased in recent years and so there a rising demand for placement outside the family.  
There is a lack of alternative residential provision for those who cannot remain with their family in the local area. This is currently being addressed by changes to the fostering process and respite provision becoming longer term. The work of the Well Child Nurse has been effective in developing a locally provided care package which can support the child at home where they have been in tertiary placements.  
The greatest increase of SEN agency placements has been for moderate learning difficulties (114% from 2012). |
| **Equipment** | Demand for equipment is increasing, which can be expected as the complexity of need is increasing.  
A new local model of equipment provision is proving to be greatly advantageous with faster turnaround, greater flexibility, greater use of recycling and decontamination of equipment and initial reports of increased family service satisfaction.  
Over 12% of all equipment is now recycled and this is increasing, with potentially large cost benefit. |
| **Social Care** | Just over 3 in 10 children supported by Social Care have SEN, with young people with BESD most likely of any SEN type to receive social care support.  
Behavioural, emotional and social difficulties are the most prevalent SEN type for children in need (26%), child protection order (38%) and looked after children (46%).  
The 2011/12 local rate of Child Protection Plans (65 per 10,000) was nearly twice the England average (38), although numbers have since fallen. |
| **Services** | Children with harder to diagnose mild or moderate disabilities or more complicated needs may not fit into service eligibility criteria so may not be receiving the services they need. |
| Partnership working | • Transparency of entitlements and thresholds for services is not currently evident  
• There is a shortage of paediatric nurses in East Sussex in emergency departments.  
• The “family approach” of the Early Help programme is working well for practitioners and service users.  
• East Sussex County Council received the highest national grading for the multi-agency transition process for meeting all statutory and guidance requirements.  
• Evidence indicates that there will be increasing pressure on social care Transition Services.  
• Acute services are currently not providing appropriate services for 16 to 17 year olds and should be more flexible particularly through transition to adult services.  
• There is service provider consensus that current financial and funding directives have made service delivery more challenging. Whilst it is felt that more efficient, joined up working through the reforms could address elements of this, it needs to be ensured that joint commissioning is improved right across disability services. |
| Short Breaks and leisure | • There have been improvements in links between specialist nurses and GPs making earlier diagnosis and support easier and more holistic.  
• Joint working between education, health and social care has improved generally with the advent of new ways of working via the SEND reforms.  
• Closer joint working, particularly via a key-worker is particularly valued as there are more same day clinical appointments made minimising the visits needed by families.  
• Short break and respite services are particularly important as opportunities for socialisation and social inclusion.  
• The numbers of children accessing short break services has increased 2.5% between 2011/12 and 2012/13. Just over 65% of all short breaks accessed in 2012/13 were either provided by residential centres or After School clubs and holiday play schemes.  
• Over the last year Autism Sussex and SCOPE have seen the greatest increase in the number of attendees and short break hours provided.  
• Preliminary data indicates just over 70% of those with i-go cards are female and 95% of those with a card have a communication need. |
| Social Inclusion | • Children and young people in East Sussex report a greater prevalence of bullying (66%) than nationally (52%), although bullying has been declining locally.  
• Young people with SEND report being bullied because of a lack of knowledge about their SEND, assumptions about their abilities, and a lack of belief that teachers are generally equipped to deal with these situations.  
• Physical access is central to inclusion and a lack of accessible transport for school classes means disabled young people have to travel |
| **Childcare** | Poverty and childcare costs; lack of appropriate places and services, and inadequate information are significant barriers to accessing childcare. |
| **Personalisation** | Early feedback on personal budgets suggests that having increased choice and control has had a positive impact for disabled children and their families as a whole, with families valuing the support plan and tending to opt for personal assistants in favour of specialist services.  
Parent perception indicates that a register of specialist nurses would be useful for parents to identify appropriate support would be useful for those with Personal Health Budgets. |
| **Gaps in provision for certain groups** | There is a parent carer perception that support is geared towards mothers looking after their child and support for secondary carers such as for separated parents could be improved.  
Small babies are surviving longer due to medical improvements such as ventilation and services are needing to provide support for greater numbers of smaller children with highly complex needs.  
Those with milder disabilities and needs or who have emotional or behavioural difficulties often do not meet service criteria so fall through the gap in provision.  
The number of children with ASD is increasing, partly due to improvements in diagnosis. Service provider and carer opinion indicates that greater support is needed than currently provided, particularly regarding mental health.  
There is a local and national perception that there is a gap in support for some 16 to 18 year olds due to differing end times of services. |
All recommendations are based on through evaluation of local and national evidence and guidelines in order to inform commissioning of SEND services in East Sussex.

In order to meet the strategic direction of the SEND pathfinder approach it is essential that:

- a) Information collection within and between services is improved and aligned.
- b) Communication across services and with children and their families is transparent and consistent.

### Service Recommendations

**RECOMMENDATION 1:** It is recommended there is a continued focus on joint working and shared outcomes to promote the further integration of services.

**RECOMMENDATION 2:** It is recommended the key-worker service is expanded to support greater numbers of children and families. This is being addressed through the current reforms to keyworker provision in East Sussex.

**RECOMMENDATION 3:** It is recommended further evaluation is needed on the work of the WellChild Nurse. Research suggests local placements enhance parent and carer wellbeing and are potentially financially beneficial for local authorities. If local evidence supports this then it is recommended this service is further developed.

**RECOMMENDATION 4:** It is recommended the potential to expand the new local model for provision of equipment is explored to further improve family service experience and reduce wastage.

**RECOMMENDATION 5:** It is recommended the range; quality and availability of short breaks continue to be developed.

**RECOMMENDATION 6:** It is recommended predicted increases in some types of SEND should be incorporated into forward planning of children’s services, particularly:

- Services for ventilated babies and those surviving longer with more complex needs
- Mental health services for children and young people with Autistic Spectrum Disorder

### Technical Recommendations

**RECOMMENDATION 1:** It is recommended data collection of information regarding children and young people with SEN/D is improved in the following ways:

1. All sectors agree a common definition of ‘disability’.
2. A database of children and young people with disabilities and/or complex health needs is developed across health, social care and education, potentially including young people whose level of need does not qualify them for SEN provision.
3. There is regular collation of service user feedback, collected at service provider level, so that this can better inform policy and practice across whole services.
RECOMMENDATION 2: It is recommended engagement with service users is improved by:

1. Continuing to build on the current development of methods to better engage parents and carers in service development and delivery. This is being developed through SEND reforms.
2. Improving engagement with children and young people with SEND in provision, design and service delivery in line with national guidance. This is being developed through SEND reforms.

RECOMMENDATION 3: It is recommended communication both with practitioners and families be improved by:

1. Providing clarity around the roles of different agencies to assist improved partnership working.
2. Agreeing common eligibility criteria across services that are made more transparent for families, referrers and providers. This will be delivered through the Local Offer.
3. Examining communication pathways and referral processes within and between services.

RECOMMENDATIONS FOR FURTHER INVESTIGATION BY CHILDREN’S DISABILITY

RECOMMENDATION 1: It is recommended further research is needed to address the dearth of information on lifestyle behaviours of children and young people with disabilities and how this impacts on their needs.

RECOMMENDATION 2: It is recommended specific research with service users and their families and carers is needed where there are gaps indicated in qualitative information. This would be subject to local research governance procedures.

RECOMMENDATION 3: It is recommended consultation is undertaken with schools and other educational settings and provision regarding the needs of children and young people with SEND and the confidence of the settings in meeting these needs.

RECOMMENDATION 4: It is recommended that social media resources such as the Information for Families’ FaceBook page are investigated as potential opportunities for engaging a wider cohort of young people and their families in service design and delivery.

RECOMMENDATION 5: It is recommended that more focused research is undertaken locally with those using personal budgets to inform future commissioning work.
I would like to acknowledge the contribution of all those who have given their time and have provided information and expertise for this Joint Strategic Needs Assessment, in particular:

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