Children with Disabilities Needs Assessment

Surrey County Council

Children's Social Care and Well Being Commissioning

October 2014

This document has been signed off by CSMT on 7th August 2014. However the content may change subject to consultation on Surrey Says.
EXECUTIVE SUMMARY

This needs analysis demonstrates the challenges for Surrey Children’s Services in providing services for children and young people with disabilities. It aims to inform commissioners, professionals and other stakeholders about areas of unmet need and the demographic demand that may affect services in the future. The current economic climate means local authorities continually have to do “more for less”. The findings of this needs assessment detail the evidence that demand for services is likely to increase over the coming years.

PREVALENCE IN POPULATION

1. **Demand will increase by approximately 9% in the next 10 years placing further pressure on services** – Population projections demonstrate that the number of 0-19 year olds will increase by 9% over the next 10 years. Factors such as better medical technology and decreasing infant mortality may cause the incidences of disability to increase.

2. **Incidents of disability are more prevalent in areas of high deprivation** – Though Surrey has lower levels of disability compared to the national average some more deprived wards have higher than average levels of disability e.g. Maybury and Sheerwater in Woking.

3. **Disabilities often mean multiple needs for children, young people and their families** - Evidence demonstrates that many children and young people have more than one disability therefore services are required that can cater for a range of complex needs.

4. **Children and young people with autism and those with complex health needs may see further increases in prevalence** - Due to better diagnosis and improved medical technology.

5. **Children and young people with severe learning disabilities often present more challenging needs, as they get older and bigger** - A larger proportion of children and young people who access disability services are in their teenage years.

PRIORITY AREAS

**Looked after Children**

58 **Children and young people** in the Children with Disabilities (CWD) Teams are looked after. Nine of these children and young people are in short break placements but these total more than 75 nights a year.

1. **Focus on Prevention**: Children and young people with disabilities often become looked after due to families and carers no longer being able to cope with the challenging needs of their disabled member of their family. If more
early support, were offered earlier, the incidences of children with disabilities becoming looked after could decrease.

2. **Develop In-County Residential School Provision** – 85% of placements in residential schools are out of county. This causes unnecessary travel between school and a child or young person’s home.

3. **Foster carers need to be given more targeted support and adaptations to their home:** To increase the number and ability of foster carers to support children and young people in a home environment with more complex needs.

**Complex Health Needs**

About 40 children and young people with disabilities have substantial needs that require additional health services. Due to improvements in medical technology, this number is likely to increase.

1. **Health and social care needs.** This group of children and young people have a combination of both health and social care needs therefore joint working between Surrey County Council and Surrey’s Clinical Commissioning Groups is required.

2. **Changes in need.** The amount of support a child, young person and their family needs can vary throughout a relatively short space of time. Some health conditions can make individuals more susceptible to other illnesses that are more prevalent at certain times of the year. Care packages need to be flexible to support these changes in need.

**Autism**

Current trends suggest that the number of children diagnosed with Autism may increase by 60% by 2020 (See section 3.4).

1. **Need for specialist services.** The capacity within specialist services currently commissioned will need to be able to cope with the potential increase in demand of services for children and young people with Autistic Spectrum Conditions.

2. **Services that support children and young people with Challenging behaviour.** Surrey has limited resources to fund services that can support children and young people with behavioural issues and this capacity will come under increasing pressure.

3. **Joint working with Special Educational Needs (SEN) and Health Services.** New legalisation will require social care services to work more closely with SEN and Health.
**Emotional Health and Well-being**

This needs assessment documents the link between children with disabilities and mental and emotional health issues.

1. **Children and young people on the autistic spectrum.** There is a need to provide specialist support addressing the emotional and mental health needs of children and young people with autism.

2. **Early intervention.** Offer early emotional wellbeing and mental health support to children and young people who are more likely to suffer from issues will decrease the dependency on specialist and acute services.

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**USER FEEDBACK**

1. **Need for joined up working:** Parents often have spoken about the need for better communication between agencies so they do not have to give their information repeatedly.

2. **Need for professionals with a knowledge of their local area.** Parents have stated that when families contact a professional, they sometimes are not aware of local services.

3. **Need to ‘Feel Safe’:** Some parents have argued that mainstream education is unsuitable for young people with disabilities. “Feeling safe” was raised by many young people as an important issue, this included being safe at school and when active in the community.

4. **Need for long term planning:** Families need ongoing support throughout their child’s life. Parents describe how complex the system is, especially the relationship between health, social care and education services.

5. **Participation, skills of professionals and access to services** were the key themes from a thematic analysis on interview data carried out by the University of Surrey on children and young people with disabilities.
RECOMMENDATIONS

1. Improve communication between partner organisations: Health, Education, and Voluntary Community and Faith Sector (VCSF). This can be done by increasing joint commissioning opportunities to reduce “silo working” of agencies working with the same children and young people.

2. Information to be open and shared between agencies so integrated services can develop, and joint commissioning opportunities can be identified.

3. Assess the family need rather the individual components that make up the family. Interventions commissioned in this way can often achieve better outcomes for each member of the family unit taking into account the resilience of the family.
   *This is now a legislative requirement.

4. Children with disabilities often have needs beyond their primary disability. A holistic, child centred approach must be used when assessing the child’s needs, for example children and young people with autism are more likely to have mental health issues.

5. Develop a joint action plan with health to meet the needs of children and young people with very complex and palliative care needs.

6. Develop a joint strategy between health, education and social care to meet the ever-increasing need of children and young people with autism.

7. Within a Children with Disabilities Commissioning Strategy there needs to be a focus on early help, prevention of families reaching crisis point, and an offer of targeted support to build up families’ resilience.

8. Work with universal services such as schools and community organisations to enable them to develop the ability to be more inclusive for those children with a disability.

9. Invest time to resource full service evaluations to assess the effectiveness of interventions and processes.

10. Commissioners to link with the performance team and identify what data they require to inform commissioning decisions.

11. CWD social work teams may need to reassess their resources to provide support for an increasing number of children and young people.

12. Preventing children and young people becoming looked after is possible by offering more support earlier before parents and carer’s reach ‘burnout’ point. However when a child or young person’s package becomes unsustainable, it is sometimes better for them to receive the stability of full time care in one placement.
13. Looked after children should be encouraged to access mainstream services as much as possible so they do not feel further detached and stigmatised. For this to happen universal services need to be able to provide a safe environment for children with disabilities and to be more inclusive.

14. Autism diagnosis rates will need to be monitored and appropriate provision needs to be developed, if the rate increases in line with the estimated projections.

15. Over the next 5 years, children and families that require support need to be identified as early as possible. Early identification of needs will allow managers to predict where pressures on services will occur as this cohort of children get older and help families to remain independent for longer.

16. The use of community support to meet the children, young people and their family’s needs should be further investigated through the market position statement.

17. Further outreach work needs to occur in specific ethnic minority communities demonstrating the services that social care can offer are able to take into account the cultural needs of individuals as well as the disability related needs.
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1. INTRODUCTION

Children and young people with disabilities have a unique and diverse range of needs and often need support from multiple agencies to meet this need and achieve their full potential. This needs analysis hopes to identify the overall need in the population of Surrey as well as studying some priority cohorts of disabled children and young people who feel their need is not being entirely met. These include:

- Children and young people with complex health needs
- Looked after children who also have a disability
- Children and young people on the autistic spectrum

There is a diverse range of data sources identifying the prevalence of need in the population. Each of these has its limitations with varying levels of data quality.

1.1 POLICY BACKGROUND

National guidelines aim for families to have all the information they need to access services for disabled children appropriately and equitably as well as being central in service planning and development. Local provision therefore should reflect choice, information and empower families to make decisions. Key areas that the government are focussing on are:

- Short breaks – Short Breaks for Carers of Disabled Children regulations 2011
- Transition to Adulthood
- Autism

Commissioning for children with disabilities can be complex with some families requiring services across health, social care and education. Nationally the government want families to have all the information they need to access services for disabled children appropriately and equitably as well as being central in service planning and development. Local provision should ensure that it reflects choice, information and empower families to make decisions.

The Children and Families Act outlines a range of key provisions for supporting children with Special Educational Needs and Disabilities. These and further legislative and local drivers are detailed in the Children with Disabilities Commissioning Strategy.
1.2 DEFINITIONS

The Disability Discrimination Act 2005 defines a disabled person as “someone who has 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”.

Surrey’s Children’s Services procedures state: “a disabled child is a child with special needs in the area of health, education, physical, intellectual, emotional, social or behavioural development due to:

- Multiple and complex health needs
- Special sense impairments: hearing loss, visual impairments or deaf-blind
- A significant learning disability
- A physical disability
- A chronic physical illness
- Autism (Autistic Spectrum Disorder) and Communication Disorders
- Significant pre-school developmental delay

The 2009 Surrey Joint Strategic Needs Assessment (JSNA) applies to a child or young person with complex needs that:

- Is aged from birth to their 25th birthday
- Has a serious ongoing illness, a chronic condition or a disability that has lasted or is expected to last at least 12 continuous months or more; and/or
- Has an illness, condition or disability that results in the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to social or physical barriers; or
- Is experiencing significant developmental or acquired impairments or delays in one or more areas of cognitive development, sensory or physical development, communication development, social, behavioural or emotional development; or
- Has a condition that has a high probability of resulting in developmental delay or deteriorating functional ability and whose ability to achieve their potential is impaired due to a wide range of barriers facing them.

Census Definition

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

Data sources

There is no central database of all children with disabilities in Surrey. Information throughout this report collates data about frequency, characteristics and geographic distribution from a number of different sources that are held within a number of different agencies. To ensure this needs assessment captures information on as many children and young people as possible a wide variety of data sources have been utilised to provide a rounded evidence base.

1. Integrated Children’s System Database

Provides information of those children and young (C&YP) people that are open to the CWD teams within SCC. There are two teams in SCC. The West team works with children and young people from Guildford, Waverley, Surrey Heath, Woking, and Runnymede. The East team accepts referrals from Elmbridge, Epsom & Ewell, Spelthorne, Mole Valley, Reigate & Banstead, and Tandridge

2. Census 2011

Within the census of 2011 there was a question asking whether an individual had a disability and whether that disability affected their life ‘a lot’ or a little’.

3. Disability Register

Surrey has a disability register for children and young people. Parents and carers are invited to give details of their disabled child or young person and receive a newsletter about disabled services in Surrey. This process is voluntary; therefore, the information from the Disability Register cannot be used in isolation.

4. Statement of Special Educational Need

Though not all children that have a statement of special educational need are disabled using the definitions on page 10, this data source does provides information on the types of disability children and young people have.

5. Services Accessed

Children and young people access a variety of services for example short breaks. Studying the amount of children accessing these services can identify demand and how that may change in the future.

6. Other Sources

These include access to disability living allowance data and carer allowance data.

All data sets were requested between October and December 2013, and by studying them all, an accurate picture can be defined of the disability cohort in Surrey. The amount of detail data sources provide varies, across agencies and collection
methods and individuals are likely to appear on more than one source. The pyramid below demonstrates visually the key data items from the key data sources.

All these sources provide different information on the needs of the children with disability cohort. In some cases they are not directly comparable, for example, the census data is talking about the 0-25 cohort while to be eligible for register the young person needs to be 18 or younger. As long as these differences are taken into account when making conclusions each data source provides an insight into the children with disability cohort that this needs assessment aims to study.
2. Surrey Picture

The following section looks at the main data sets available when assessing the profile of children with disabilities. All the major data sets have their drawbacks and therefore they will be assessed individually. The first of these is the Census of 2011.

2.1 Census 2011 Data

In the census, respondents were asked whether they had a disability or health condition that was expected to last 12 months and had an impact on their day-to-day activities. The following tables and maps show this data for the 0-15 age cohort and then the 16-24 age cohort. It details those children and young people that responded that their disability “affected their life a lot”.

0-15 age

Surrey has a lower proportion of children with disabilities that have day-to-day activities limited compared to national and regional averages in 0-15 age category. Research has demonstrated that levels of disability are lower in families within professional and managerial backgrounds. The affluent general population of Surrey therefore may explain why disability levels are lower compared to other local authorities nationally. Surrey does have pockets of deprivation and within these areas, levels of disabilities tend to be high (see Figure 2).

<table>
<thead>
<tr>
<th>Region</th>
<th>All people aged 0 to 15</th>
<th>Day-to-day activities limited a lot</th>
<th>% Day-to-day activities limited a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surrey</td>
<td>216289</td>
<td>2466</td>
<td>1.1</td>
</tr>
<tr>
<td>South East</td>
<td>1626989</td>
<td>22563</td>
<td>1.4</td>
</tr>
<tr>
<td>England</td>
<td>9982575</td>
<td>153101</td>
<td>1.5</td>
</tr>
</tbody>
</table>
The table and map demonstrate there are some distinct variations between the number of children with disabilities among the different district and boroughs. Population differences mean Guildford and Reigate & Banstead have the largest population of children and young people aged 0-15 with a disability. Spelthorne has the largest proportion. It also, in 2010, had the highest indices of deprivation.

Indeed primary research demonstrates that there is a strong correlation between poverty and disabilities. It is a two way process, disability adds to the risk of poverty and the conditions of poverty add to the risk of disability.
The ward map demonstrates that children and young people with disabilities are spread throughout the county with pockets of more densely populated areas. The six areas identified have the highest amount of children with disabilities, they also have relatively high levels of deprivation (IMD 2010) compared to other wards in the county, this is especially true of the Maybury and Sheerwater area and the Ashford North area that are in the top five wards when measuring the indices of deprivation.

The Index of Multiple Deprivation 2010 (IMD 2010) combines a number of indicators, chosen to cover a range of economic, social and housing issues, into a single deprivation score for each small area in England. The Indices of Deprivation 2010 has been produced at ward level and allows each area to be ranked relative to one another according to their level of deprivation.
16-25
Compared to the national and regional picture Surrey has a lower proportion of 16-25 young people with disabilities.

TABLE 3 CENSUS 2011 NUMBER OF 16-25 Responds who had Day to Day Activities Limited (County)

<table>
<thead>
<tr>
<th>Region</th>
<th>All people aged 16 to 24</th>
<th>Day-to-day activities limited a lot</th>
<th>% Day-to-day activities limited a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surrey</td>
<td>105599</td>
<td>1628</td>
<td>1.5</td>
</tr>
<tr>
<td>South East</td>
<td>896785</td>
<td>16481</td>
<td>1.8</td>
</tr>
<tr>
<td>England</td>
<td>5901807</td>
<td>116091</td>
<td>2.0</td>
</tr>
</tbody>
</table>

TABLE 4 CENSUS 2011 NUMBER OF 16-25 Respondents who had Day to Day Activities Limited (District & Borough)

<table>
<thead>
<tr>
<th>Region</th>
<th>All people aged 16 to 24</th>
<th>Day-to-day activities limited a lot</th>
<th>% Day-to-day activities limited a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elmbridge</td>
<td>10545</td>
<td>158</td>
<td>1.5</td>
</tr>
<tr>
<td>Epsom and Ewell</td>
<td>7584</td>
<td>117</td>
<td>1.5</td>
</tr>
<tr>
<td>Guildford</td>
<td>14942</td>
<td>211</td>
<td>1.4</td>
</tr>
<tr>
<td>Mole Valley</td>
<td>7169</td>
<td>122</td>
<td>1.7</td>
</tr>
<tr>
<td>Reigate and Banstead</td>
<td>12543</td>
<td>216</td>
<td>1.7</td>
</tr>
<tr>
<td>Runnymede</td>
<td>9355</td>
<td>102</td>
<td>1.1</td>
</tr>
<tr>
<td>Spelthorne</td>
<td>9371</td>
<td>149</td>
<td>1.6</td>
</tr>
<tr>
<td>Surrey Heath</td>
<td>7953</td>
<td>139</td>
<td>1.8</td>
</tr>
<tr>
<td>Tandridge</td>
<td>7429</td>
<td>128</td>
<td>1.7</td>
</tr>
<tr>
<td>Waverley</td>
<td>9628</td>
<td>142</td>
<td>1.5</td>
</tr>
<tr>
<td>Woking</td>
<td>9080</td>
<td>144</td>
<td>1.6</td>
</tr>
</tbody>
</table>

Reigate and Banstead, and Guildford have the highest number of individuals with a disability or health condition. Tandridge has the largest proportion of 16-24 year olds with a disability or health condition whilst Elmbridge has the lowest. The ward map demonstrates that deprivation perhaps still plays a role in the distribution of Young people with disabilities with Maybury and Sheerwater having the largest number of young people with disabilities. There also seems to be a concentration of individuals around Guildford in Westborough and Stoke for this age group.
FIGURE 3 CENSUS 2011 16-25 COUNTY MAP OF YOUNG PEOPLE WITH A DISABILITY THAT LIMITED DAY TO DAY ACTIVITY A LOT

FIGURE 4 CENSUS 2011 16-25 WARD MAP OF YOUNG PEOPLE WITH A DISABILITY THAT LIMITED DAY TO DAY ACTIVITY A LOT
2.2 DISABILITY REGISTER

The Surrey Children’s Disability Register is a voluntary register. Parents can register eligible children aged less than 18 years, who live in Surrey and meet both registration criteria, and these are detailed below:

1 (a) has a serious ongoing illness, a complex chronic condition or a disability that has lasted or is anticipated to last at least 12 continuous months or more; and/or

(b) Has an illness, condition or disability that results in the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to social or physical barriers.

2 (a) is experiencing significant developmental or acquired impairments or delays in one or more areas of cognitive development, sensory or physical development, communication developments, social behavioural or emotional development; or

(b) has a condition that has a high probability of resulting in developmental delay or deteriorating functional ability and whose ability to achieve their potential is impaired due to a wide range of barriers facing them.

Being voluntary, the register does not provide a complete picture of the population of children with disabilities in Surrey. The advantage to parents of registering their children is that they will be on a mailing list for consultations, and information about changes to services, including short breaks, holiday and after school schemes and activities.

The geographical location of those on the register is not significantly different to the proportion of children and young people within the district and boroughs.
The age of those on the register is detailed in figure 6. 11-15 year olds are the most represented age group. As children and young people with certain disabilities get older, they may display behaviour that is more challenging that parents and carers need support to manage, this can especially be the case with teenage boys. Parents of this age cohort may be more interested in receiving the benefits that the register offers.

The disability register also includes information on the nature of the disabilities that respondents have defined. The table and chart below demonstrate that nearly 50% of those on the register have a learning difficulty identified.
### TABLE 5 DISABILITY REGISTER BREAKDOWN OF DISABILITY

<table>
<thead>
<tr>
<th>Nature of Disability</th>
<th>Number of Individuals on the register</th>
<th>% on register</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behaviour</td>
<td>562</td>
<td>27%</td>
</tr>
<tr>
<td>Communication</td>
<td>967</td>
<td>47%</td>
</tr>
<tr>
<td>Diagnosed with Autism or Asperger's syndrome</td>
<td>882</td>
<td>43%</td>
</tr>
<tr>
<td>Disabled under DDA but not in the other categories</td>
<td>185</td>
<td>9%</td>
</tr>
<tr>
<td>Hand function</td>
<td>3</td>
<td>0%</td>
</tr>
<tr>
<td>Hearing</td>
<td>161</td>
<td>8%</td>
</tr>
<tr>
<td>Learning</td>
<td>1016</td>
<td>49%</td>
</tr>
<tr>
<td>Mobility</td>
<td>229</td>
<td>11%</td>
</tr>
<tr>
<td>Vision</td>
<td>241</td>
<td>12%</td>
</tr>
</tbody>
</table>

![FIGURE 7 CHART SHOWING % OF INDIVIDUALS BY DISABILITY TYPE ON THE DISABILITY REGISTER](image)

The geographical location of those on the register demonstrates that areas of deprivation have more children and young people signed up to the register. Team
managers suggest that the register is not advertised equitably amongst all the districts and boroughs and therefore does not offer an accurate reflection of disability across Surrey.

The disability register also has information about children and young people’s health condition; this was recorded on 60% of the records on the register. The table below demonstrates the most common health conditions recorded. 27% had a developmental delay, the majority of these were 10 or under and represented undiagnosed conditions such as autism.

TABLE 6 WARD BREAKDOWN OF DISABILITY REGISTER

<table>
<thead>
<tr>
<th>Wards</th>
<th>Number of Individuals of Disability Register</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maybury and Sheerwater</td>
<td>36</td>
</tr>
<tr>
<td>South Park and Woodhatch</td>
<td>30</td>
</tr>
<tr>
<td>Westborough</td>
<td>29</td>
</tr>
<tr>
<td>Staines South</td>
<td>28</td>
</tr>
<tr>
<td>Knaphill</td>
<td>27</td>
</tr>
<tr>
<td>Kingfield and Westfield</td>
<td>27</td>
</tr>
<tr>
<td>Stoughton</td>
<td>26</td>
</tr>
<tr>
<td>Leatherhead North</td>
<td>26</td>
</tr>
<tr>
<td>Worplesdon</td>
<td>24</td>
</tr>
<tr>
<td>Sunbury Common</td>
<td>21</td>
</tr>
</tbody>
</table>

The majority of individuals only had 1 health condition however a significant number, more than 150 had 3 or more health conditions, this demonstrates the complex needs of some cases and though they may not qualify for continuing health care, present a significant challenge to Children’s Social Care teams as well

TABLE 7 HEALTH CONDITIONS RECORDED OF THOSE ON THE DISABILITY REGISTER

<table>
<thead>
<tr>
<th>Health Condition</th>
<th>Number of Individuals on the Register</th>
<th>% of individuals on the register</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental Delay</td>
<td>556</td>
<td>27%</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>197</td>
<td>10%</td>
</tr>
<tr>
<td>Physical Disability</td>
<td>184</td>
<td>9%</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>118</td>
<td>6%</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>172</td>
<td>8%</td>
</tr>
<tr>
<td>ADHD</td>
<td>67</td>
<td>3%</td>
</tr>
<tr>
<td>Severe Language Disorder</td>
<td>85</td>
<td>4%</td>
</tr>
<tr>
<td>Chromosome Disorder</td>
<td>67</td>
<td>3%</td>
</tr>
<tr>
<td>Asperger Syndrome</td>
<td>35</td>
<td>2%</td>
</tr>
</tbody>
</table>

TABLE 8 NUMBER OF HEALTH CONDITIONS THAT PEOPLE ON THE REGISTER HAVE RECORDED

<table>
<thead>
<tr>
<th>Number of Health Conditions</th>
<th>Number of Individuals on the register</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>833</td>
</tr>
<tr>
<td>1</td>
<td>712</td>
</tr>
<tr>
<td>2</td>
<td>391</td>
</tr>
<tr>
<td>3</td>
<td>118</td>
</tr>
<tr>
<td>4</td>
<td>27</td>
</tr>
<tr>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Grand Total</td>
<td>2089</td>
</tr>
</tbody>
</table>

Figure 8 demonstrates changes in the number of people on the disability register over the past 5 years. Since October, the number of children and young people on the register has continued to increase.
The number of children and young people on the register has increased since October 2011.

**2.3 CHILDREN AND YOUNG PEOPLE RECEIVING DISABILITY LIVING ALLOWANCE (DLA)**

Children and Young People receiving Disability Living Allowance (DLA) can claim Disability Living Allowance (DLA) if there is medical evidence of their disability. Figure 9 shows that the number of DLA claimants aged 0-24 in Surrey increased from 1,180 to 1,910 between January 2008 and January 2014 representing a 61% increase in the last 8 years.
The DLA can be received as a care component and a mobility component. Children can claim the care component if they require significantly more help or supervision than their peers or if they:

- Need help with washing, dressing, eating, getting to and using the toilet, or communicating their needs
- Need supervision to avoid putting themselves or others in substantial danger
- Need someone with them when they are on dialysis
- Are unable to prepare a cooked main meal for themselves (they are aged 16 or over).

Children can claim the mobility component of DLA if they are:

- Unable, or virtually unable, to walk or would be at risk if they tried to walk
- Both 100 per cent disabled because of loss of eyesight and not less than 80 per cent disabled because of deafness (age three and above)
- Severely mentally impaired with severe behavioural problems and qualify for the highest rate of care component (age three and above)
- If they need guidance or supervision when walking out of doors (age five and above).

2.4 CHILDREN WITH DISABILITIES RECEIVING SOCIAL CARE SERVICES

Access to social care services is based on eligibility criteria that are detailed here:


Children who access the CWD teams have:

- A serious life-threatening or life-limiting condition or a disability that has lasted or is anticipated to last at least 12 continuous months or more;
- An illness, condition or disability that results in the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to social or physical barriers;
- Significant developmental or acquired impairments or delays in one or more areas of cognitive development, communication development, sensory or physical development

The following data details those open cases from a report run on the 24/10/13.
Children with Disability (CwD) Open Cases

The number of C&YP open to the CWD teams from the 11 district and boroughs within Surrey varies in proportion to the overall population of 0-19

![Chart showing borough breakdown of CwD open cases](image)

**FIGURE 10 CHART SHOWING BOROUGH BREAKDOWN OF CWD OPEN CASES**

Guildford and Reigate & Banstead have the highest number of open cases and Epsom & Ewell have the lowest. From previous sections of the report, we can see this is relatively consistent with projected numbers of children with disabilities in Surrey.

The majority of these cases are open to the East and West CWD teams however; some are open to other teams within Children's Social Services. One explanation for this could be the movement of workers into different teams while still keeping cases attached to them. The 132 cases that are not assigned to a CWD team are based throughout the other teams of the directorate with the highest number being 14 in the fostering team. The area based Referral, Assessment and Intervention teams have 28 cases also recorded as Children with disabilities.

**Main Category of Need – Open Cases**

As expected the main category of need for those recorded as having a disability on ICS is CH: N2 Child’s disability, however 200 cases have a different main category of need, demonstrating the complex nature of some of the children and young people open to Surrey children’s social services.
### TABLE 9 MAIN CATEGORY OF NEED OF CWD OPEN CASES

<table>
<thead>
<tr>
<th>Row Labels</th>
<th>Category of Need – CWD</th>
</tr>
</thead>
<tbody>
<tr>
<td>AD: Hearing Impairment</td>
<td>1</td>
</tr>
<tr>
<td>AD: Learning Disability</td>
<td>1</td>
</tr>
<tr>
<td>CH: N1 Abuse or Neglect</td>
<td>74</td>
</tr>
<tr>
<td>CH: N2 Child’s Disability</td>
<td>619</td>
</tr>
<tr>
<td>CH: N3 Parent Ill Disabled</td>
<td>12</td>
</tr>
<tr>
<td>CH: N4 Fam Acute Stress</td>
<td>67</td>
</tr>
<tr>
<td>CH: N5 Family Dysfunction</td>
<td>37</td>
</tr>
<tr>
<td>CH: N6 Soc Unacceptable Behaviour</td>
<td>3</td>
</tr>
<tr>
<td>CH: N8 Absent Parent</td>
<td>1</td>
</tr>
<tr>
<td>CH: N9 Cases Not CIN</td>
<td>5</td>
</tr>
<tr>
<td>Grand Total</td>
<td>820</td>
</tr>
</tbody>
</table>

### Access to Social Care Trends

Access to social care services is dependent on a number of factors, eligibility criteria, demand, and publicity of how to access social care. What is clear from other section is the need of the population is going to increase due to a number of reasons:

1. **Population Increase**

   Birth rate has increased over the past 10 years; this is due to two main factors. Firstly, the grand children of the original baby boom generation in the late 1940s – early 1950s are having children. Secondly, internal migration from other areas of the country and from other countries continues to be higher than Surrey emigration.

2. **Medical Technology**

   As medical technology continues to advance the number of children living through birth and early years increases. This not only means there is a greater number of children and young people who are in need of a social care intervention but also the complexity of the care needs is greater. This will put greater pressures on practitioners who will need to give support that is more intensive.
FIGURE 11 – NUMBER OF C&YP OPEN TO THE CWD TEAMS

The graph above shows the number of open cases in the CWD teams throughout the last 3 years. The team in the west of the county has seen a 12% increase in the number of open cases over the past 3 years, while the east saw a decline between September 11 – September 12 but has been increasing since then. Overall, there are consistently slightly more cases in the east compared to the west.

**Future Projections**

Access to social care does not seem to correlate to population due to constraints on capacity and changes in eligibility. The following graph demonstrates changes in the need presuming eligibility criteria remain the same and population projections are the main driver behind increases in access.
The graph shows that demand for social services is likely to increase until at least 2027 based on population projections. With contributing factors such as advances in medical technology, also causing an increase in the disability population as well as better diagnosis and conditions such as autism the graph is likely to be a conservative estimate on the future demand for services.

**Recommendation:** With more people eligible for social care services, the challenge to find efficiency savings will be even harder. More effective working between partners and the development of inclusive universal services that have the capacity to provide opportunities to children with disabilities offer an opportunity to make efficiency savings while providing the same levels of support for children young people and their families.
3. PRIORITY AREAS

3.1 LOOKED AFTER CHILDREN WITH A DISABILITY

58 children and young people in the CWD team are also looked after. These children are placed throughout the county and beyond depending on their need and what placements are available for them. The following charts demonstrate the location and type of placements.

**FIGURE 13 IN AND OUT OF COUNTY PLACEMENT LOCATION**

**FIGURE 14 DISTRICT & BOROUGH BREAKDOWN FOR CHILDREN WITH DISABILITY FOR ARE ALSO LOOKED AFTER**

Looked after children with disabilities are in a variety of different placement types. Residential schools make up a third of the placements, followed by homes and hostels. 17 of the of the 21 placements in residential schools are out of county, while...
16 of those in homes and hostels or children’s homes within Surrey are placed in county.

Compared to other looked after children those in the CWD teams have relatively stable placements. 17 children and young people have been looked after for more than two and half years and 15 of these have been in their current placement for more than 2 years. This 88% stability rate is larger than the other Looked after Children area based teams.

The majority of looked after children with a disability are 10 or above with currently (15.03.14) only eight children looked after who are under 10. This demonstrates how children with disabilities often become more challenging for parents and carers to support as they get older. The 8 children under 10 are placed in foster care. The following graph demonstrates age plotted against number of months looked after. The large cluster of cases 14-17 who have been looked after for 20 months or less demonstrates that caring for young people with certain disabilities at this age can be challenging.

![Figure 15: Age of looked after children by duration looked after](image_url)

Research has demonstrated that looked after children are more likely to suffer from significant emotional and mental health issues (Aileen Blower, 2004). This cohort especially therefore needs a co-ordinated response between Surrey County Council and partner agencies. Research has also demonstrated that this group of children and young people are often wary of accessing support services that make them feel further stigmatized (Aileen Blower, 2004); support needs to work around making the individuals feel included in mainstream society.
Recommendation: Preventing children and young people becoming looked after is possible by offering appropriate early help care packages earlier before parents and carer’s reach ‘burnout’ point

Recommendation: Looked after Children should be encouraged to access mainstream services as much as possible so they do not feel further detached and stigmatized. For this to occur universal services need to be able to provide a safe environment for children with disabilities

Further Work: Impact needs to be assessed of in county and out of county placements on the outcomes for children and young people

3.2 PUPILS WITH A STATEMENT IN SURREY

Children with Special Educational Needs (SEN) have learning difficulties or disabilities that make learning harder for them than for other children of the same age. Their difficulties may be cognitive, physical, sensory emotional, behavioural, social or with communication. Special Educational Needs could be the result of:

- Developmental delay leading to slower learning
- Known disability or health problem for example hearing loss, visual impairment, physical disability or a medical condition
- Speech and language delay or disorder leading to difficulties with communication and understanding
- Emotional or behavioural difficulties affecting the ability to learn
- A condition such as dyslexia

Children with the most demanding educational needs will be provided with a Statement of Special Educational Need setting out their needs in detail and the special educational provision to be made. As of January 2013, there were 5,643

Level of Need in Population

The chart below shows how little the number of children with SEN has fluctuated since 2009.
However though this trend overall shows no significant change studying the age break down of those pupils in Surrey with a statement there are small differences over the last 5 years.

The chart demonstrates that certain age groups have experienced an increase over the past 5 years. The 2-5 year old age group is example of this having increased by 37% over the past 5 years. Earlier diagnosis of conditions such as autism as well as increasing birth rate over the past 5 years could go some way to explain this. In addition, children are increasingly entering school settings at a younger age with proliferation of reception classes connected to schools rather than independent nurseries.

Recommendations: Provision for pupils with a statement needs to include children in reception to year 3.

Recommendation: The new Education and Health Care Plans offer an opportunity to recognise the need for early intervention within the early years of a child’s life.

A needs analysis for this cohort is already in the process of being published so this section will briefly touch on some of the key findings from this cohort.
In January 2013 there were 5,383 children and young people aged 0-19 in Surrey who had Statements of Special Educational Need. Almost one in four (24%) had ASD and 22% of young people had SLCN. 17% had Moderate Learning Difficulties (MLD) and 11% had Behavioural, Emotional and Social Difficulties (BESD). The proportions of young people with Severe Learning Difficulties (SLD) and profound and multiple learning difficulties (PMLD) increase significantly from year 12 onwards, reflecting the higher level of needs generally associated with young people in these categories.

- 1,000 more young people aged 4-25 with SEND by 2033 (↑ 9.8%) and 300 more aged 16-25 (↑ 5.1%)
- 134 young people with SEND in years 12-14 were NEET at the end of January 2013. Following the introduction of the Ready 4 Work programme this had reduced to 82 on 3rd October 2013
- A projected significant shift in the needs of young people with SEND towards Autistic Spectrum Disorders (ASD) – an additional 3,200 young people aged 4-25 (↑ 190%) by 2033 – away from Moderate Learning Difficulties (MLD) (↓ 73%) and Specific Learning Difficulties (SpLD) (↓ 88%)
- Projections suggest the North East of the county could experience the most growth in numbers of young people with SEND 16-25 (↑ 19%) followed by the North West (↑ 12%)
- Young people aged 16-25 with ASD are currently twice as likely to access Special School provision than the overall population and the average cost of placing a young person with ASD is estimated to be 90% higher than placing someone with MLD or SpLD
- The highest growth forecast, as a result the Children and Families Bill 2013, identifies that numbers of young people wishing to take up provision 19-25 could increase by 3,500 by 2033 and costs could increase by 94% by 2023 or 250% by 2033 on current levels.

Like many of the other cohorts of Children with disabilities pupils with a statement are more likely to come from areas of deprivation. In June 2013, there were 2,484 young people with a statement in years 5 to 10. Of these 566 (22.8%) were eligible for free school meals. This compares to only 9.3% of pupils without a statement being eligible for free school meals. Therefore, young people with a statement are twice as likely.

**Recommendation:** Autism diagnosis rates will need to be monitored and appropriate provision needs to be developed if the rate does increase in line with these estimates. These include short break units that can cope with challenging behaviour.
3.3 CHILDREN WITH COMPLEX HEALTH NEEDS

Children and young people with complex health needs often need multiple agency involvement with in care, a need for respite for the parents or carer and technology. Care packages for this cohort especially therefore need to take a family orientated approach as the whole family unit may need some form of support.

The Level of Need in the Population

There is no definite definition of complex health needs and therefore it is very difficult to assess the level of need in the population. Those children and young people that qualify for continuing healthcare also would be defined as having complex health needs.

Deep Dives

Looking in depth at some ICS records for these complex cases, we can see the extent of support that is required for some children and young people and their families and a better multi agency approach is needed to achieve the best outcomes for these children, young people and family. It is well established that the range, diversity and different levels of support add an extra burden to families with children and young people with complex health needs as they try to find out what support they are eligible.

Many of the complex cases involve rare and poorly understood conditions. Medical and social research around best practice and the need of children with these specific conditions is often realised. Some of these conditions include:

- Muscular Dystrophy
- Mitochondrial Disease
- Waardenburg Syndrome
- Microcephaly
- Complex epilepsy

The rarity and complexity of these conditions often means that specific services do not exist to cater for the needs of this cohort. The case notes and case summaries of the children and young people do give some indication of some of the needs that are often apparent throughout the children and young people identified.

Mobility

Children and young people are often very immobile in this cohort therefore services need to be localised. Due to the specialist needs of this cohort the availability of a local services that can meet their needs is variable across the county. The presence of additional technical and medical equipment can make going out very difficult or impossible for these families with children or young people with complex health needs. Commissioned services therefore need to able to deliver on flexibility,
mobility and the ability to provide children and young people with same freedom to do the things they enjoy doing.

Technology

Children with complex health needs and their families have all the same needs of services and support as other disabled children but have the added specific need of medical technology. The study of cases on ICS demonstrated that many individuals were dependent on medical technology to compensate for the loss of a vital bodily function such as ability to breathe or feed independently. Many of the families had been visited by an occupational therapist

Changes in Need

The needs of families with children or young people with complex needs can often change regularly and frequently. This can be due to a number of factors, those with complex health needs are often more vulnerable to the affects of seasonal flu for example. Packages of care therefore need to be adaptable and all agencies need to communicate effectively to manage the flexibility within a care package. However, the needs and problems faced by this cohort cannot be just defined through the assessments of need through an individual’s conditions or impairments but also societal values that often place barriers towards those children with complex needs (Horwath, 2001).

Recommendation: Link with health partners to define eligibility criteria for both Social Care and continuing healthcare support. More defined boundaries will allow appropriate individuals to be signposted to appropriate organisations.

3.4 CHILDREN ON THE AUTISTIC SPECTRUM

Previous sections have demonstrated that those children on the autistic spectrum make up a sizeable group of children with disabilities. 43% of children and young people on the disability register had autism or aspergers syndrome, while 24% of those with a SEN Statement were categorised as ASD as their primary need. The needs of those with autism and their family or carer can vary greatly depending on the resilience of the individuals and the severity of the condition.

Level of Need in the Population

The proportion of children identified with autism on the annual School Survey is demonstrated in the chart below. Research suggests that the rise in autism s due to a number of factors however the literature and expert groups seem to agree that
increased awareness and better diagnosis is one of the main reasons for this increase (Rutter, 2005). Though the trend for diagnosed autism is increasing, the literature has speculated that in the near future this rate of increase will start to decline.

Those with less severe autism on the most part stay in mainstream school. However, this cohort still has some need that could be addressed in the context of the early help agenda. Research has demonstrated that friendship quality and frequency of contact is lower in those children and young people that have ASD (Neysa Petrina, 2013). Parenting a child with an ASD is often associated with high levels of stress (Ciara Foody, 2013) and their support provided must take into account the needs and wishes of the carers.

**Future Projections**

Though the literature suggests that the upward trend may slow down in the coming years currently the data shows no signs that this is occurring the following graph demonstrates future projections based on the past 5 years worth of data.
The following graph demonstrates a continuation of the upward trend identified over the past 5 years. At the current rate of increase by 2020, the number of children with autism will reach 2,500. As the rate of autism increases, however, the rate of those diagnosed with a general learning difficulty has been decreasing.

**Recommendation:** A market position statement will detail how the market can be developed to manage the expected increase in demand.

**Further Work:** The reasons behind the decreasing level of children and young people with a learning difficulty is unclear and further investigation is needed.

### 3.5 Emotional Well Being and Mental Health

Research demonstrates that there is a strong link between children with disabilities also having emotional and mental health needs. Research by (Eric Emerson, 2007) reported that 36% of children with a learning disability have a diagnosable mental health condition. The stigma associated with disability can often cause social anxiety; all professionals that work with children with disabilities need to be aware of the signs of emotional vulnerabilities and specific mental health conditions.

Children with learning disabilities are:

- 33 times more likely to have an autistic spectrum disorder
- 8 times more likely to have attention deficit hyperactivity disorder (ADHD)
- 6 times more likely to have a conduct disorder
- 4 times more likely to have an emotional disorder
- 1.7 times more likely to have a depressive disorder

Nearly 8 out of 10 young people with learning disability have experienced bullying. (Burke, 2014)

The Foundation for People with Learning Disabilities (Burke, 2014) project found that the complex needs of this group of children are not always understood, as professionals do not always recognise mental health problems. Professionals often see Mental Health problems related to learning disability and do not make specialist referrals. Other issues include services are often not available, inappropriate with long delays before receiving assessment and young people being shunted between mainstream and specialist services. For those aged between 16 and 18 years it is unclear if they are seen by local mental health or learning disability services and often not seen by any service, a particular issue for those with mild or moderate learning disabilities.

The Foundation for People with Learning Disabilities (Burke, 2014) also found that research shows the ‘Friends for Life’ school based programme can reduce anxiety and depression, increase coping skills and self esteem and is considering how this can be adapted for children with learning disabilities. It incorporates resilience and mindfulness onto a social-emotional developmental and cognitive behavioural framework.
4. FUTURE NEED

4.1 POPULATION PROJECTIONS

The population of children and young people with disabilities is dependent on a number of factors that are difficult to predict, this includes medical advances, improved diagnosis and treatment as well as population changes. The latter of these is the only one of these that can be predicted with any confidence.

The following table demonstrates the predicted population changes (ONS) in 2015-2025.

**FIGURE 20 POPULATION PROJECTIONS FOR 0-19 AGE COHORT**

<table>
<thead>
<tr>
<th>Local authority</th>
<th>0 – 19 years 2015</th>
<th>0 – 19 years 2025</th>
<th>% increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elmbridge</td>
<td>33,800</td>
<td>35,800</td>
<td>5.9</td>
</tr>
<tr>
<td>Epsom and Ewell</td>
<td>19,400</td>
<td>22,500</td>
<td>16.0</td>
</tr>
<tr>
<td>Guildford</td>
<td>34,200</td>
<td>37,000</td>
<td>8.2</td>
</tr>
<tr>
<td>Mole Valley</td>
<td>19,900</td>
<td>21,000</td>
<td>5.5</td>
</tr>
<tr>
<td>Reigate and Banstead</td>
<td>35,000</td>
<td>39,200</td>
<td>12.0</td>
</tr>
<tr>
<td>Runnymede</td>
<td>19,800</td>
<td>21,900</td>
<td>10.6</td>
</tr>
<tr>
<td>Spelthorne</td>
<td>22,100</td>
<td>24,200</td>
<td>9.5</td>
</tr>
<tr>
<td>Surrey Heath</td>
<td>21,000</td>
<td>21,400</td>
<td>1.9</td>
</tr>
<tr>
<td>Tandridge</td>
<td>21,000</td>
<td>22,400</td>
<td>6.7</td>
</tr>
<tr>
<td>Waverley</td>
<td>32,300</td>
<td>34,100</td>
<td>5.6</td>
</tr>
<tr>
<td>Woking</td>
<td>24,300</td>
<td>27,000</td>
<td>11.1</td>
</tr>
</tbody>
</table>

Population projections suggest that over a 10 year period the 10-19 cohort is going to increase significantly. This suggests that currently we are in a period of high births. Disability needs and potential support should therefore be identified as early as possible to help ease the pressure on services in the future.

**Recommendation:** Over the next 5 years, children and families that need support need to be identified as early as possible. Early identification of needs will allow managers to predict where pressures on services will occur as this group of children get older.
The chart above assumes migration levels will be low over the next 10 years, however some areas within Surrey have relatively high levels of migration and within these areas, we may expect to see a higher birth rate. Reigate and Banstead and Runnymede are predicted to have the highest levels of migration over the next 10 years.

Recommendation: Areas which see high levels of migration need to be monitored and services put in place to respond to the changing need of children with disabilities within local communities.

4.2 PROJECTING CHILDREN AND FAMILIES THAT WILL BE ELIGIBLE FOR OUR SERVICES

Projecting those individuals that may access social care services in the future is heavily dependent on National and local drivers that constantly change eligibility criteria to services that local authorities provide. As the previous section identifies the 10-19 population in the next 10 years is going to see a marked increase and presuming the level of disability stays the same in the population there will be more children and young people eligible for Social Care services. With resources for services diminishing over the next 10 years, we will expect to see an increase in demand with less economic capital to provide them.

Recommendation: Friends, family and community support needs to be developed as a viable option to help children, young people and their families.
Disabilities may be developmental or acquired and specific causes can often be due to multiple factors rather than just one identifiable main factor. Prevention of disabilities in children is sometimes possible through genetic counselling and neonatal screening however, as a society there is a need to remove the barriers associated with disability so the needs of this cohort can be met the community and the mainstream of society rather than by expensive intrusive professional interventions.

5.1 CAUSES OF DISABILITIES IN CHILDREN

Chromosomal and Genetic Abnormalities

Mutations can occur in anyone and are very difficult to predict. However once a mutation has occurred it can then be passed down generations meaning those offspring of parents with a mutations have an increased likelihood in also carrying the mutation and its consequences. Genetics is a very complex topic therefore genetic counselling can work as a way for potential parents to understand the potential risk of having children.

Prematurity, low birth weight and neonatal care

Babies are recorded as premature when they are born at least four weeks before the due date. The long-term effects of prematurity on development depend on how early the infant is born, its birth weight, the type of postnatal care it receives, and the quality of its environment during early and middle childhood. With medical help, many premature babies will develop without any significant health issues; however, there is an approximate 20% chance of disability.

The following chart shows the rate of live births that are born under 2500g
Woking and Spelthorne have the highest rate of live births who are born under 2500g both these areas have wards with some of the highest levels of deprivation (Maybury and sheer water and Stanwell & Ashford north). Social determinants for poor health, such as deprivation, can lead to a greater number of premature babies; this was detailed in the Marmot Review 2010

**Infant Mortality**

Figure 23 shows that surrey has low rates of infant mortality compared to the rest of its Statistical Comparators; this could suggest that a greater proportion of children with complex health needs may be living longer. However, it may also be down to other factors such as increased rates of poverty in neighbouring counties that are correlated too higher levels of infant mortality.

![Infant Mortality 2011-12](image)

**FIGURE 23 INFANT MORTALITY 2011-12**

**Hospital Admissions 0-5 years**

**TABLE 10: 0-5 YEARS OLD HOSPITAL ADMISSIONS**

<table>
<thead>
<tr>
<th>Admission</th>
<th>2008-09</th>
<th>2009-10</th>
<th>2010-11</th>
<th>2008-11</th>
</tr>
</thead>
<tbody>
<tr>
<td>All admissions 0-5 years</td>
<td>14107</td>
<td>16620</td>
<td>20300</td>
<td>51027</td>
</tr>
<tr>
<td>With SEN conditions - 0-5 years</td>
<td>1942</td>
<td>2810</td>
<td>3614</td>
<td>8366</td>
</tr>
<tr>
<td>Percentage (%) with SEN conditions</td>
<td>13.8</td>
<td>16.9</td>
<td>17.8</td>
<td>16.4</td>
</tr>
</tbody>
</table>

The number of hospital admissions increase significantly between 2008 and 2011. This is especially true of those admissions of children with a SEN condition. This may be due better diagnosis for the early year’s cohort as well as increasingly number of children with complex health needs surviving beyond one year. Support for complex health needs relies too heavily
on emergency hospital admission, if more support was available in the community this could lower the number of hospital admissions, potentially saving money and achieving better outcomes for children and young people. It would also allow children and young people to be released from hospital earlier into safe community based care.

**Recommendation:** Social care and health colleagues to work together to develop services that can prevent the need for children and young people to enter hospital and provide services for children when they are discharged from hospital.
6. DEMOGRAPHIC AND EQUALITY

A number of characteristics are protected under the disability discrimination act the following description gives details on how members with these differing characteristics.

Gender

Males are more likely to access the CWD teams. This is due to two main influences, firstly certain genetic conditions are more likely to affect males, it has been hypothesised that autism for example is linked to genes on the x chromosome, as males have only have one x chromosome they are more likely to show the effects of that chromosome. Other research suggests also that males are more likely to be diagnosed with autism and aspergers. This is because the trigger for diagnosis is often disruptive behaviour, which is a lot more common in boys than girls even though they may have the same underlying condition. Challenging behaviour amongst boys can become especially difficult for carers and parents to manage when they approach adulthood and get physically stronger. This perhaps may explain the chart below that details that there is greater number of males in the CWD teams

**Gender of children open to CWDTeams**

![Gender Chart]

- Male: 65%
- Female: 35%

Age

Access to services also seems to be affected by age, though actually the 0-4 cohort is the largest 5-year age band in terms of children and young people in the population but the lowest age band in terms of accessing the CWD team’s services. Again, a number of factors may influence this. The most prominent of these is how certain conditions manifest themselves within the different age groups. Older children can often have Increasing incidents of challenging behaviour and therefore the parents often need increasingly amount of support as children move into their teenage years.
FIGURE 24 AGE OF C&YP OPEN TO THE CWD TEAM

Recommendation: By identifying children and young people earlier on in their lives, preventative services can be put in place that will allow parents and carers to cope for longer when their child reaches an older age.

Ethnicity

Certain ethnic minorities demonstrate a higher prevalence of disabilities and therefore carers often face a greater burden of care. In some instances, support services on offer have been shown to culturally inappropriate for some groups. The causes for higher disability prevalence rate within certain communities are complex with both environmental and genetic reasons having an effect. Services need to be able to meet the cultural needs of all children and young people in Surrey as well as their social care needs.

The pie chart shows that people accessing services from the CWD teams are nearly identical to the proportion of ethnicities in the general population. As stated above certain
minority populations do have increased prevalence of disability, therefore work needs occur engaging specific communities. For example, the gypsy/roma community only has one individual accessing social care; previous work carried out in Leicestershire city council demonstrated the distrust of this community accessing statutory services. Certain communities also feel a stronger sense of duty towards caring for family members therefore are less likely to request support from social services.

**Recommendation:** Further outreach work needs to occur in specific ethnic minority communities demonstrating the services that social care can offer are able to take into account the cultural needs of individuals as well as the disability related needs.
7. NEEDS IDENTIFIED FROM USER FEEDBACK

7.1 USER CONSULTATION

1. **Need for joined up working**: Parents often have spoken about the need for greater link up between agencies so they do not have to give their information repeatedly.

2. **Need for professionals with a knowledge of their local area**: Parents have stated that, when families contact a professional, they are often have a lack of knowledge of local services.

3. **Need to ‘Feel Safe’**: Some parents have argued that mainstream education is unsuitable for young people with disabilities. “Feeling safe” was raised by many young people as an important issue, this included being safe at school and when active in the community.

4. **Need for long term planning**: Families need ongoing support throughout their child’s life. Parents describe how complex the system is, especially the relationship between health, social care and education services.

A report carried out by Barnardo’s about user’s views of the services they received also demonstrated areas of need for the Children with disabilities.

Participation: Young people and children often still feel that professionals communicate with their parents rather than talking to them. They feel their views should be at the centre of provision provided for them. Information needs to be provided in a way that makes it accessible for children and young people so they can make an informed choice about the decisions that affect them.

Professionals: Most disabled young people feel that most professionals listened to them and responded their needs; however this was not always the case and most reported a mixed picture across establishments. A more consistent approach is needed across providers regarding the recruitment and training of staff.

Access: Disabled young people perceive cost and transport to be the main barrier towards them accessing the services they wish too. Many of the older young people reported feeling that provision seemed to cater for younger age groups. There seems to be limited opportunity to mix with non-disabled young people increasing the feeling of stigmatisation that disabled young people feel.

The consultation demonstrated that social networks and relationships were the most important areas for disabled young people. Services therefore need to promote developing friendships and enabling them to have high quality time with their family.
University of Surrey performed a detailed study on out-of-school play and leisure activities for children (age 4-11) in Surrey with particular reference to families with disabled children. This analysis identified areas of unmet need among Children with Disabilities population.

Non-disabled respondents were reported to be participating in a significantly larger number of activities than children from all disabled groups. Children with complex needs participated in less than half of the amount of activities compared to their non-disabled counterparts. Barriers to accessing activities for Disabled Children in Surrey include lack of information, transport and limited choice.

Short breaks service provided by Surrey County Council offered a number of beneficial outcomes for service users and their parents and carers in Surrey, rest (respite), improved family functioning / reduced stress, allowing them to work, train or study, providing time for themselves and to socialise, and to spend with other siblings.
5. MAPPING OF CURRENT SERVICES

A selection of services are made available directly through the local authority as well as provided by the private, voluntary and faith sectors to support disabled children and young people. The Market Position Statement will detail this service provision.

5.1 SHORT BREAKS

Surrey Short Breaks for Disabled Children (previously known as Aiming High for Disabled Children Surrey) funds voluntary organizations and SEN Schools to provide short break services ranging from afterschool clubs to holiday schemes, home care and more. The majority of these services do not require eligibility for social care support from SCC.

Access to short breaks has increased over the past 5 years even through the budget for the service has stayed the same. Increased publicity and awareness of the scheme by parents with disabled children is considered the main catalyst for this increase.

![Figure 25 Chart showing the numbers of families accessing short breaks](chart)

The market position statement will detail areas of development needed from the market.

FIGURE 25 CHART SHOWING THE NUMBERS OF FAMILIES ACCESSING SHORT BREAKS
6. CONCLUDING REMARKS

This needs analysis has covered a large breadth of the information surrounding the children and young people with disabilities cohort in Surrey. There any many components of the children and young people with disability cohorts that could be studied further to assess their individual needs including: visual impairment, hearing impairments, learning disabilities, epilepsy, physical disabilities etc. By focussing on the breadth of the disability cohort in Surrey as well as some priority areas, key implications for Surrey County Council and our partners have been evidenced.

1. Demand for all services will increase in the future

**How to can we meet the need?** Focus on prevention services earlier on a child’s life this will decrease family breakdown as their child gets older.

2. The number of children diagnosed with autism will increase

**How can we meet the need?** Develop the market for specialist services in county for children and young people with autism. Services that can cope with challenging behaviour are especially needed in Surrey.

3. Areas of high deprivation also see high levels of disability

**How can we meet the need?** Outreach work in areas of high deprivation can make families access services before the reach crises point and need high cost specialist interventions

4. Children with Complex Health needs require both a social care and health input.

**How can we meet the need?** Develop a joint action plan with health to meet the needs of children and young people with very complex and palliative care needs

**Further Work**

The legalisation around children with disabilities is currently undergoing a large change. The introduction of an integrated assessment and a **single Education, Health and Care Plan (EHCP)** to replace the present Statement of Educational Need will offer a chance to incorporate many of the recommendations from this needs analysis during the same period of transition. The increased uptake of direct payments by parents and carers will also have a big impact on how commissioning takes place in the future. Parents and carers will therefore drive the market in the direction they feel is suitable for their children. Commissioners therefore will need to make sure they are closely linked with the social work teams to have a constant picture of the types of services parents want to purchase. Finally, joint commissioning opportunities between health and social care need to be realised. For this to occur a jointly agreed needs analysis, commissioning strategy and market position, need to be agreed with health colleagues.
WORKS CITED


Feedback on Children with Disabilities Needs Assessment:

We are always looking to improve our understanding of children and young people with disabilities needs in Surrey.

Please send any feedback direct to James Holden, Commissioning Project Officer in the Children’s Social Care and Well Being Commissioning Team.

Email: james.holden@surreycc.gov.uk