KENT PUBLIC HEALTH OBSERVATORY

Disabled children and young people needs assessment summary

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Produced by

Jo Tonkin: Public Health Specialist (jo.tonkin@kent.gov.uk)

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Disabled Children and Young People

Introduction

Children living with disability, and their families, are a heterogeneous group of people with individual needs which may vary in complexity and may change over time. Responding to the needs of children living with disability can be a challenge for commissioners and providers of services to support these children. This needs assessment aims to facilitate greater understanding of the needs of children living with disability and to support the development and improvement of these support services.

There are a range of difficulties which may be experienced by a child living with disability including issues with[1]:

- mobility
- manual dexterity
- physical co-ordination
- communication
- sensory impairment (e.g. hearing or visual impairment)
- memory, concentration and learning
- recognising physical danger
- continence.

In addition, some children with chronic illness controlled by medication may meet the Disability Discrimination Act (DDA) definition of having a disability.

Learning Disability[2]

The Department of Health defines learning disability as a significantly reduced ability to understand new or complex information, to learn new skills and a 'reduced ability to cope independently which starts before adulthood with lasting effects on development'[3]. A learning disability may be classified as mild, moderate or severe depending on degree of difficulties with communication and cognition.

[1] Blackburn CM, Spencer NJ, Read JM. (2010) *'Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey'*. BMC Paediatrician Apr 16; 10:21-2431-10-21.
[2] Department of Health. (2001) 'Valuing *People: A New Strategy for Learning Disability for the 21st Century'*. https://www.gov.uk/government/publications/valuing-people-a-new-strategy-for-learning-disability-for-the-21st-century Accessed 02/06/2016
[3] DH (2002) ' *Valuing People: a New Strategy for Learning Disability in the 21st Century'* https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf Accessed 30/12/2016

Profound and Multiple Learning Disabilities (PMLD)

The term profound and multiple learning disabilities is used when a child is living with more than one disability. This includes a learning disability in association with sensory impairment, physical disability, complex health needs and/or mental health difficulties. Children with PMLD often have high care needs and need support with most activities of daily living. The carers of children with PMLD are also likely to have significant needs for social and emotional support.

Language Disorders

Language disorders in children may be receptive, i.e. there is a difficulty understanding (or 'receiving') messages coming from others, expressive, i.e. there is a difficulty expressing messages to others, or a combination of these difficulties. In language disorders, speech and language do not develop normally. This is in contrast to delayed language in which speech and language development is normal but occurs later than average age.

Language disorders may occur in children with other developmental disorders, autism spectrum disorder, hearing impairment and learning disabilities. Brain injury may also cause language disorders.

Dyspraxia/Developmental Coordination Disorders (DCD)[4]

Developmental coordination disorder (DCD), which is also sometimes known as dyspraxia, is associated with impairment of physical coordination. DCD may lead to delays in the child achieving developmental milestones associated with coordination, such as crawling and self-feeding, and skills in writing or sports may be behind what is expected for their age.

It should be noted that DCD is distinct from conditions with more general developmental delay, and from cerebral palsy and other neurological conditions.

Attention Deficit Hyperactivity Disorder (ADHD)[5]

Attention deficit hyperactivity disorder (ADHD) is associated with behavioural symptoms including inattentiveness, hyperactivity and impulsiveness. ADHD may also be associated with difficulties sleeping and anxiety. ADHD is more common in boys than girls. The symptoms of ADHD often improve with age, although some adults continue to experience problems. ADHD is more common in children with a learning disability; however it can occur in the absence of any learning disability.

[4] NHS Choices. (2016) '*Developmental coordination disorder (dyspraxia) in children*'. http://www.nhs.uk/conditions/Dyspraxia-(childhood)/Pages/Introduction.aspx. Accessed 05/19/ 16.
[5] NHS Choices. (2016) '*Attention deficit hyperactivity disorder (ADHD)*' http://www.nhs.uk/Conditions/attention-deficit-hyperactivity-disorder/Pages/Introduction.aspx. Accessed 05/01/2016.

Autism Spectrum Disorders (ASD)[6]

Autism spectrum disorder (ASD) is a condition associated with difficulty with communication, behaviour and social interaction. Children with ASD will often show signs of the condition before the age of three years. ASD is diagnosed in boys more commonly than in girls. The prevalence of ASD is approximately 10/1000 in the UK.

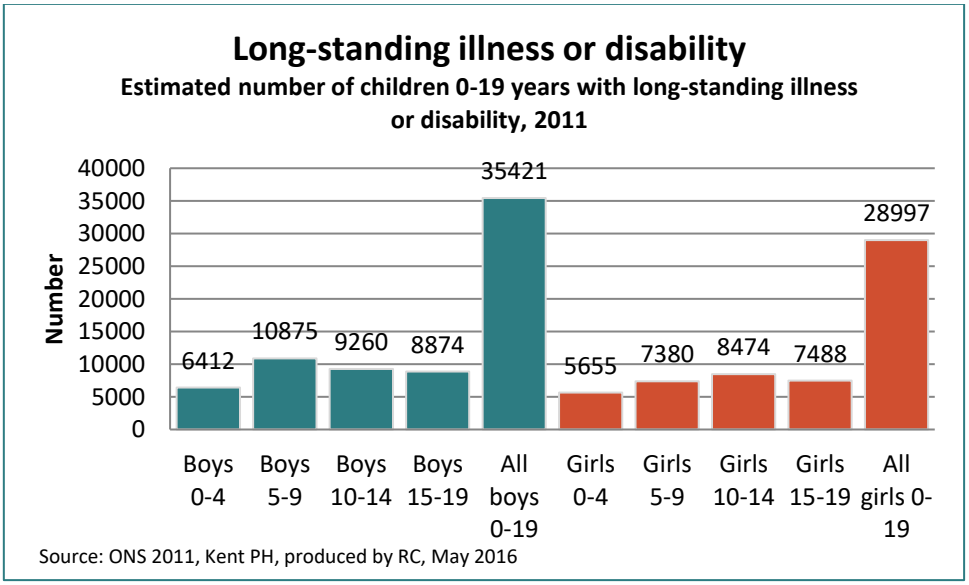
Physical Disability[7]

A physical disability is a physical condition which limits a person's movements and/or control of movements, senses or activities. There are many causes of physical disabilities in children, the most common causes include muscular dystrophies, spina bifida, cerebral palsy and acquired injuries. Physical disability may occur independently, or may be associated with other disabilities such as learning disabilities or sensory impairment.

Disabilities may be developmental or acquired. Sometimes, several factors may combine to cause a disability and often the exact cause is unknown. There are however recognised risk factors: chromosomal and genetic abnormalities; mother and baby having different blood types; infectious diseases suffered by mothers and children; premature birth and/or low birth weight babies; foetuses being exposed to drugs and/or radiation; poor maternal nutrition; maternal use of drugs and alcohol.

Epidemiology

Figure 1: Prevalence of long-standing illness and disability in children and young people in Kent

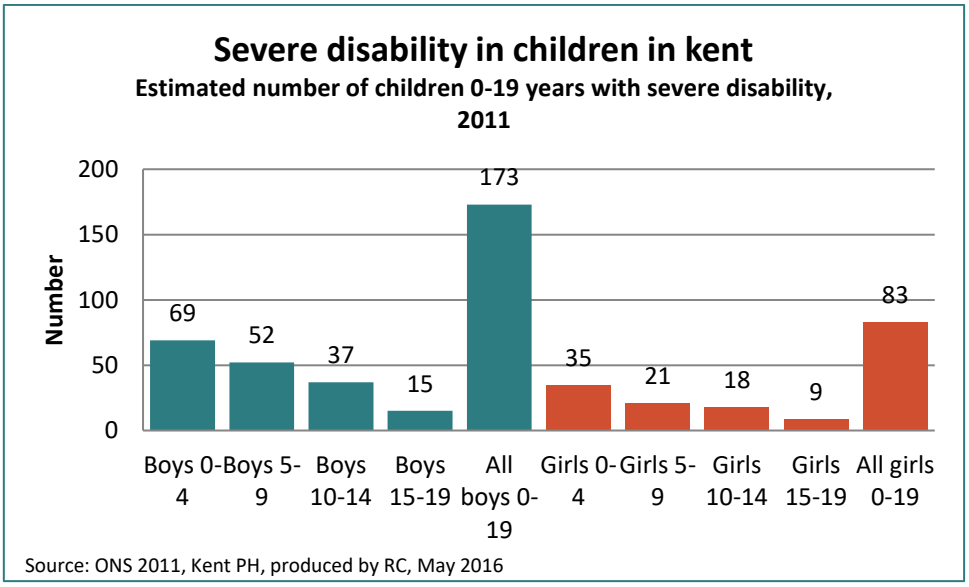


[6] NHS Choices. Autism spectrum disorder (ASD). Available at: http://www.nhs.uk/conditions/Autistic-spectrum-disorder/Pages/Introduction.aspx. Accessed 05/19, /2016.

[7] Women's and children's health network. '*Physical disability*'. http://www.cyh.com/HealthTopics/HealthTopicDetails.aspx?p=114&np=306&id=1874. Accessed 19/05/2016.

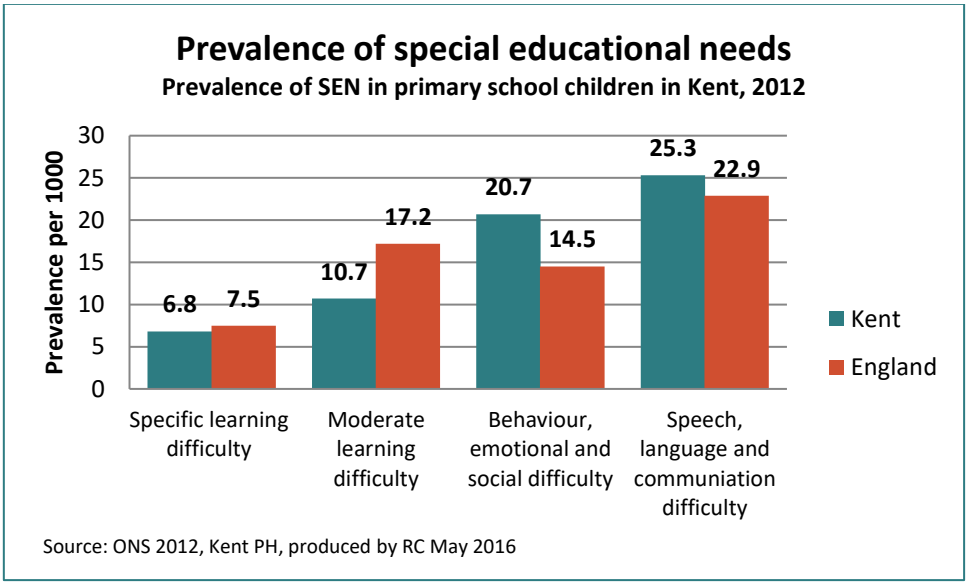
The figure above shows the expected number of children aged 0-19 years in Kent with long-standing illness or disability.

Figure 2: Severe disability in children in Kent



The number of boys with a severe disability is higher than the number of girls at all ages. The number of children with severe disability decreases with age due to significant mortality in children with severe disability.

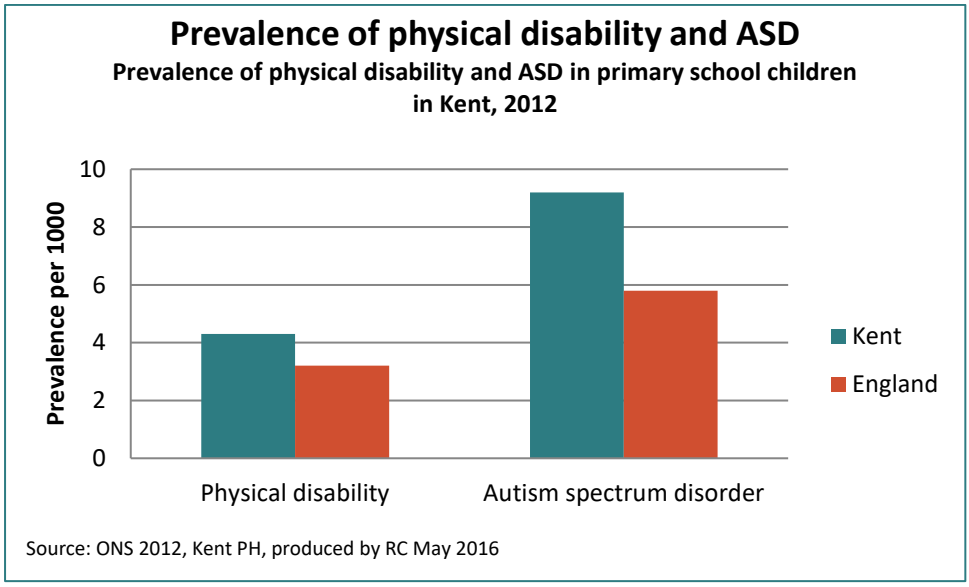
Figure 3: Prevalence of special educational needs in children and young people in Kent Primary Schools



The prevalence of specific and moderate learning difficulty was lower in Kent than in England, while the prevalence of behavioural, emotional and social difficulty, and speech, language and communication difficulty was higher. The prevalence of severe learning

difficulty in Kent at 1.20 per 1000, and of profound and multiple learning difficulties in Kent at 0.5 per 1000 was similar to levels seen nationally.

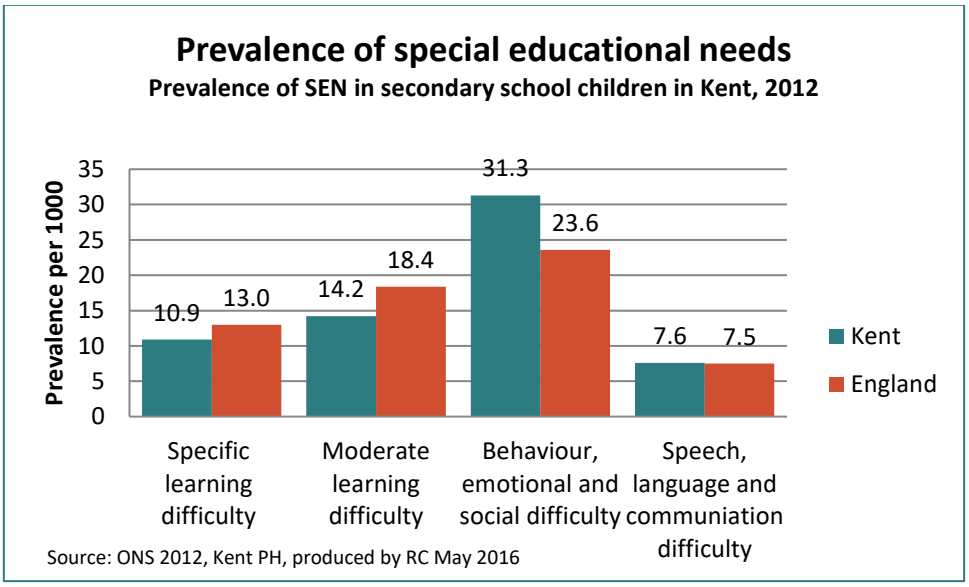
Figure 4: Prevalence of physical disability and ASD



The prevalence of physical disability per 1000 was higher in Kent at 4.30 per 1000, than in England at 3.20 per 1000. The prevalence of ASD was higher in Kent at 9.2 per 1000, than in England at 5.8 per 1000.

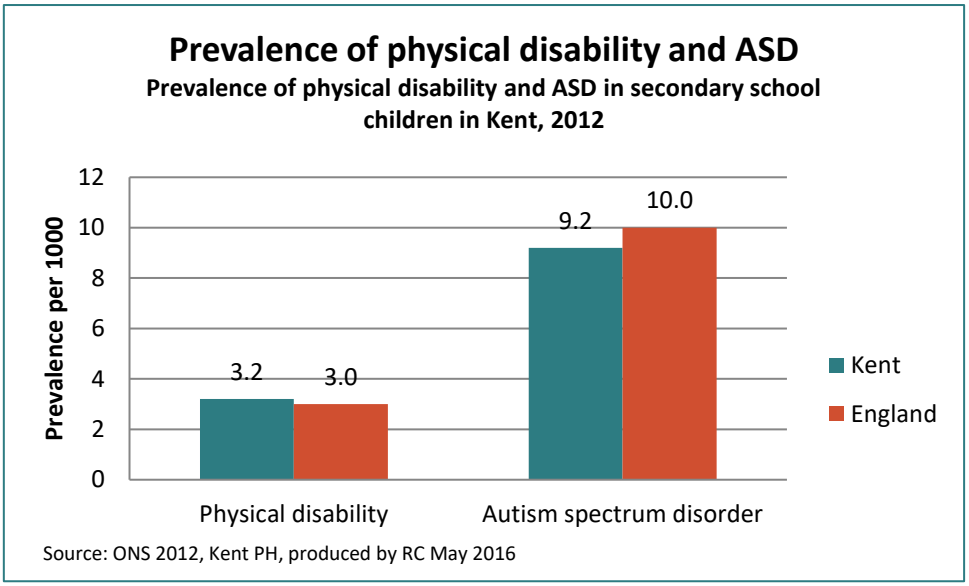
Secondary Schools

Figure 5: Prevalence of special educational needs



The prevalence of severe learning difficulty and profound and multiple difficulty in secondary school children was similar in Kent and England.

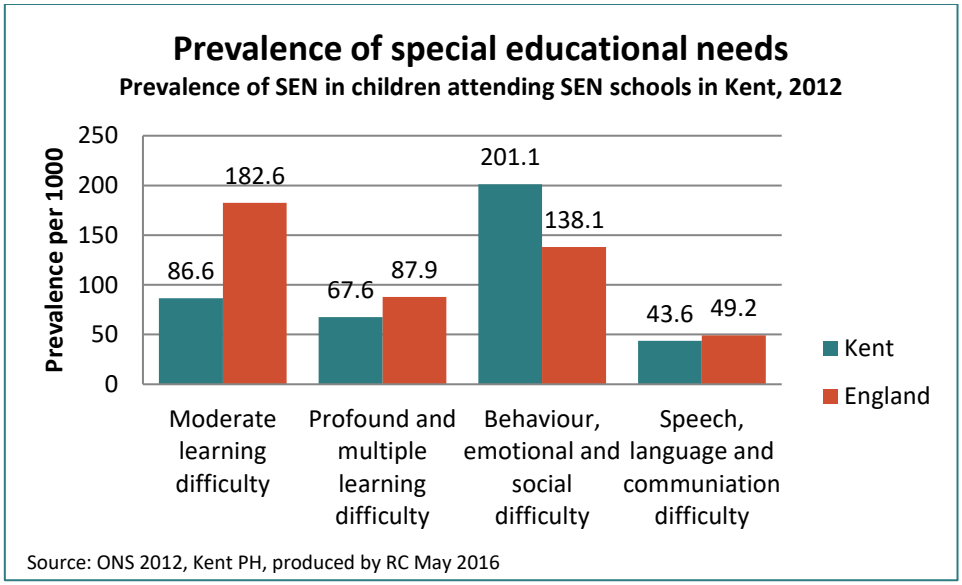
Figure 6: Prevalence of physical disability and ASD



The prevalence of ASD in secondary school children in Kent was slightly lower than that noted in England, which is a reverse of the pattern seen in primary school children demonstrated above.

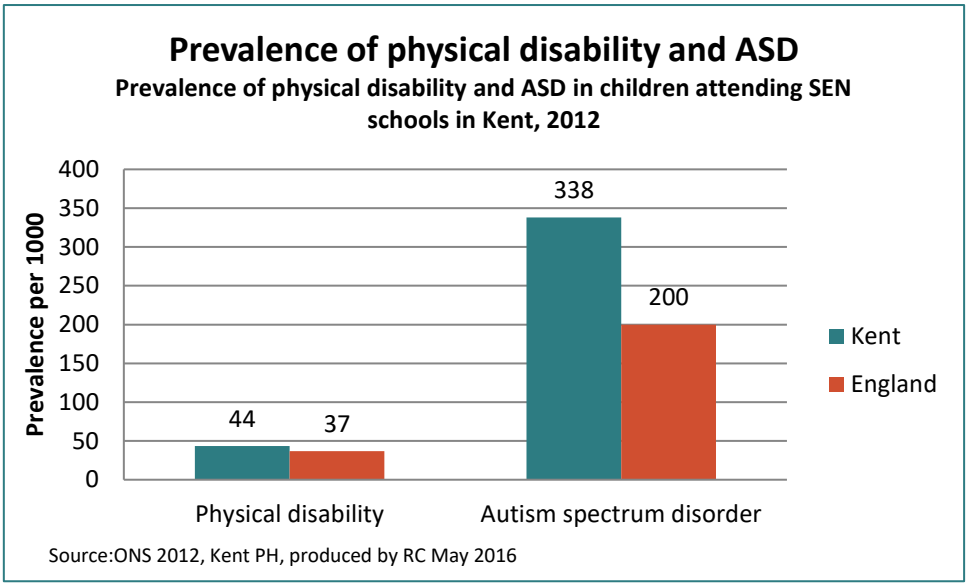
Special Educational Needs Schools (SEN)

Figure 7: Prevalence of special educational needs



The prevalence of moderate learning difficulty, profound and multiple learning difficulty, and speech, language and communication difficulty was lower locally than nationally, while behavioural, emotional and social difficulty was more prevalent in Kent than England.

Figure 8: Prevalence of physical disability and ASD



The prevalence of physical disability in children attending SEN schools is slightly higher in Kent than in England. The prevalence of ASD in children attending SEN schools is higher in Kent than England.

Table 1: Projected changes in the number of children living with disability in Kent 2013-2033

Prevalence of learning disabilities up to age 24 in Kent CCGs, 2013 projected to 2033
Children known to schools and adults 18-24 known to local authorities

CCG	2013	2018	2023	2028	2033	Period % change
Ashford	438	454	478	494	499	**14.0**
C4	671	683	702	713	710	**5.8**
DGS	875	921	982	1021	1037	**18.5**
SKC	649	633	649	651	647	**-0.4**
Swale	394	416	444	461	469	**19.0**
Thanet	463	481	510	524	529	**14.1**
West Kent	1648	1709	1801	1858	1886	**14.4**
Kent	**5,139**	**5,296**	**5,566**	**5,721**	**5,777**	**12.4**

Source: Derived from Public Health England by KPHO

ASD/ ADHD

In 2013 the estimated number of children living with Autism Spectrum Disorder (ASD) was 4,906, or 3.3 per 1000. This is expected to increase to 5,434 children by 2033. The estimated number of children in Kent living with ADHD was 20,446, or 13.8 per 1000. This is projected to increase to 22,628 children by 2033.

Sensory Impairment

The number of children and young people living with blindness was estimated 232, or 0.2 per 1000, in 2013. This is expected to increase to 252 children and young people by 2033. The number of children and young people expected to have partial sight was estimated to be 695, or 0.5 per 1000, in 2013. This is projected to increase to 758 by 2033.

The prevalence of deafness in children and young people up to age 24 was estimated to be 0.3 per 1000, or 395 individuals. The prevalence of hard-of-hearing was 0.09 per 1000, or 135 individuals, in 2013. These figures are expected to increase to 422 individuals and 144 respectively by 2033.

Health Risks to Children and Young People who are Disabled and Access to Preventative Health Care

Children and young people with disabilities are at risk of being incontinent, of being overweight and obese and of obesity related health conditions including asthma, diabetes, muscular skeletal and cardiovascular conditions. They are also at risk of poor emotional and mental health, of problematic substance misuse, of poor sexual health, of sexual, physical and emotional abuse and are vulnerable to sexual exploitation. This may result from a clustering of health and social disadvantage.

Table 2: Estimated number of children with learning disability and mental health problem by age[8]

	Children aged 5-9 yrs with a learning disability with mental health problems (2014)	Children aged 10-14 yrs with a learning disability with mental health problems (2014)	Children aged 15-19 yrs with a learning disability with mental health problems (2014)
Kent	360	790	1,015

Source: Office for National Statistics midyear population estimates for 2014. CCG population estimates aggregated from GP registered populations (Oct 2014).

Children in Care

There was an increase in the number of Kent children in care with a disability (from 92 in 2011/12 to 141 in 2013/14). In 2013/14, 70 Kent children in care had a learning disability.

In March 2014, there were 141 children in care with a disability record. Forty-three per cent (61 children) had a legal status of being accommodated under Section 20 of the Children's Act. Eighteen per cent (25 children) were placed outside Kent.

In February 2015, Kent had a total of 94 children in care with disabilities. Of these 65 are supported by the East Kent disabilities teams and the remaining 29 by the West Kent team.

Young People engaged with the Youth Justice System (YJS):

It is understood that young people who offend have a higher percentage of learning disability than the non-offending population. It is estimated that 25 to 30% of children and young people in the YJS have learning disabilities, and that this rises to around 50 % of those

in custody. Chitsabesan (2006) found that one in five young offenders identified as having a learning disability. Hughes (2012) reports that generalised learning disability is significantly more common in young people in custody than the wider population 'with research studies suggesting a prevalence of 23-32%, compared to 2-4% of the general population'. Hughes goes on to note that 'specific reading difficulties, such as dyslexia, appear significantly more common in young people who offend, with research studies suggesting a prevalence of between 43 and 57%, compared to around 10% of the general population'[9].

Findings and Recommendations

The population of children and young people with disabilities is forecast to increase in line with increases in the child population in Kent.

Commissioning

Commissioners take action to:

- prevent and mitigate against risks which may cause children and young people to be disabled
- address inequities and insufficiencies of health, social care and education provision across Kent
- ensure care is well coordinated around the needs of the child and family
- seek feedback from parents and carers and children and young people to ensure the best possible outcomes for children and young people
- ensure that children and families with disabilities are included in any actions to address health inequalities and child poverty in Kent
- work to reduce smoking, drug and alcohol in pregnancy and promote good nutrition in young women prior to conception and in pregnancy. This includes ensuring the distribution of Healthy Start vitamins
- increase breastfeeding initiation and at six – eight weeks
- ensure that children with at risk of and with disabilities have access to the comprehensive offer of health protection, screening and assessment including immunisations and vaccinations
- identify opportunities for developing holistic assessment of needs and health promotion in relation to developmental milestones, weight management, dental health, emotional and mental health, substance misuse, sex and relationships across the life course for children with disabilities including entry to special schools, monitoring of health need by health visitors, children's community nursing

[9] Hughes et al (2012) 'Nobody made the connection: the prevalence of neuro disability in young people who offend' https://www.childrenscommissioner.gov.uk/sites/default/files/publications/Nobody%20made%20the%20connection.pdf Accessed 22/12/2016

- ensure access of those young people with learning disabilities who are registered aged 14 plus to a developmentally appropriate annual health review
- map provision and utilisation of services in Kent for children and young people with disabilities in line with increasing population needs to understand any inequalities and insufficiencies in service delivery including immunisations , vaccinations and screening and address gaps in delivery.
- Address gaps where they are already identified:
    - vision Screening in West Kent
    - incontinence at level 2 in West and North Kent and enuresis at level 2 across Kent
    - access to ADHD and ASD diagnosis in East Kent
    - access to emotional and mental health support for children and young people with disabilities
    - access to sexual health services and Personal Social Health Education (PSHE) for young people with learning disabilities and information and support for their parents and carers
    - access to therapies including Speech and Language Therapy (SALT)
    - access to community nursing and special school nursing.
- explore benefits and opportunities for joint commissioning building on the evidence of the North Kent Joint Commissioning Model and the Multi Agency Service Hub
- ensure sufficiency in educational settings in order to address gaps in attainment / progress for children with SEN
- progress the utilisation of education health and care (EHC) plans
- Ensure that EHC are shared and care coordinated with CIC , CIN , Care and Support and YOS Care Plans
- ensure the views of children, young people and parents and carers, are systematically collected, and informs service development.

Informatics

- Accurate recording of childhood disabilities is problematic with multiple sources in health and in education applying different definitions of disability. There is therefore a need to ensure all providers are contributing to Children and Young People's Health Services (CYPHS) data set and working to improve data quality.
- Promote and build family engagement in the Kent Disability Register.
- Agree standard categories and data fields and use them across services and commissioning, embedding them within contracts and improving data compliance and quality.
- Progress the flow of data to the Kent Integrated Dataset (KID).