

Children and Young People with Disabilities

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Introduction

Giving every child the best start in life and enabling children and young people to maximise their potential are two of the key recommendations of the 2010 Marmot review of health inequalities in the UK 'Fair Society, Healthy Lives'¹. Improving the health and wellbeing of children has a long-term impact that carries on into adulthood, and reduces health inequalities.

Children and young people living with a disability may face particular difficulties in achieving their potential related to the physical and/or intellectual impairment, or to the impact this has on their ability to participate in activities and society.

In seeking to understand the health inequalities experienced by children with learning disabilities, Eric Emerson for Public Health England reported, that they are:

- *'more likely to live in households characterised by low socio-economic position and poverty; they are also more likely to be exposed to recurrent poverty and to become poor; they are less likely to escape from poverty*
- *more likely to be exposed to a wide range of material and psychosocial hazards that are detrimental to their health, including inadequate nutrition, poor housing conditions, exposure to environmental toxins, family, peer and community violence, poor parenting and family instability - this increased risk of exposure is likely to result from the combined effects of the link between child learning disability and poverty and systemic and overt discrimination faced by people with learning disabilities in England*
- *less likely to have access to the resources necessary to build resilience in the face of adversity*².

The purpose of this JSNA chapter is to consider what is meant by 'disability' in children, to understand the prevalence and the difficulties in estimating it, and identify recommendations for commissioning which may prevent or mitigate the risks of children being disabled or improve the effectiveness of current services for children who are disabled. This chapter should be read alongside the JSNA chapters on Sensory Impairment, Neuro Disability, Emotional and Mental Health.

¹ Institute of Health Equity (2010) 'Fair society, healthy lives'
<http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review> Accessed 05/12/2016

² PHE (2015) ' The determinants of health inequities experienced by children with learning Disabilities'
http://www.improvinghealthandlives.org.uk/securefiles/160826_1222//Determinants%20of%20Child%20Health%20Inequalities.pdf Accessed 05/12/2016

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.

Defining Disability³

Defining 'disability' is complex given the different theoretical interpretations of the word. The 'medical model' of disability considers that disability is present where a physical or psychological illness and/or impairment exists that limits the ability or activities of a person and may decrease their quality of life. The Disability Discrimination Act (DDA) definition assumes the 'medical model' defining a person with a disability as someone who has a physical or mental impairment which has a substantial and long-term adverse effect on his/her ability to carry out normal day-to-day activities. In contrast the 'social model' of disability highlights the societal barriers a person with impairment or illness may encounter, e.g. the absence of a ramp for wheelchair access or for adjustment of text for people with visual impairment, as the primary cause of disability⁴.

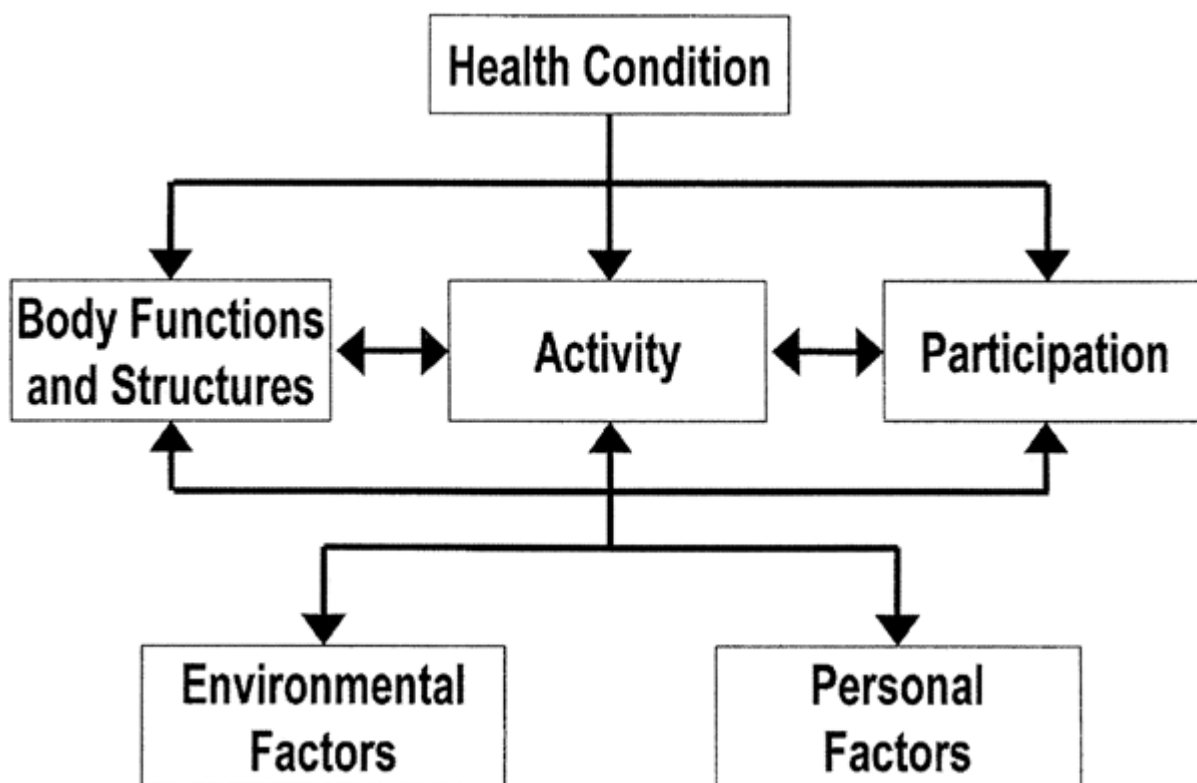
Both models of disability are useful in assessing the level of need of the wide variety of persons, both children and adults, who live with disability. The medical model can facilitate epidemiological assessment of need and identification of people living with disability. The 'social model' facilitates consideration of the 'bigger picture' and challenges us to identify both need and opportunities/solutions at a societal level. The WHO has tried to incorporate both individual and societal elements of disability in their International Classification of Functioning, Disability and Health (ICF). Within the ICF 'disability' and 'functioning' are viewed as outcomes of the interaction between health conditions or states and contextual factors including environmental factors (e.g. access to educational support) and personal factors (e.g. resilience, gender, age)⁵.

³ See also the definition of Sensory Impairment in the JSNA chapter 'Sensory Impairment' <http://www.kpho.org.uk/joint-strategic-needs-assessment/jsna-population-groups/jsna-sensory-impairment>

⁴ BMA Board of Science (2013) 'Growing up in the UK'. <https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/child-health/growing-up-in-the-uk> Accessed 02/12/2016

⁵ World Health Organisation(2002) 'Towards a common language for functioning, disability and health' <http://www.who.int/classifications/icf/icfbeginnersguide.pdf?ua=1> Accessed 11/06/2016.

Figure 1: Model of Disability



Source: WHO, 2002

There are a range of difficulties which may be experienced by a child living with disability including issues with⁶:

- 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 DDA definition of having a disability.

A number of key definitions to consider within disability are given below.

⁶ 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.

Learning disability⁷

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'⁸. A learning disability may be classified as mild, moderate or severe depending on degree of difficulties with communication and cognition.

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)⁹

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.

⁷ 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

⁸ 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

⁹ NHS Choices.(2016) '*Developmental coordination disorder (dyspraxia) in children*'. [http://www.nhs.uk/conditions/Dyspraxia-\(Childhood\)/Pages/Introduction.aspx](http://www.nhs.uk/conditions/Dyspraxia-(Childhood)/Pages/Introduction.aspx). Accessed 05/19/ 16.

Attention deficit hyperactivity disorder (ADHD)¹⁰

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.

Autism spectrum disorders (ASD)¹¹

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 disability¹²

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.

Who is at Risk and Why?

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

Disabilities such as Down's syndrome, sickle cell disease and phenylketonuria¹³ can be caused by chromosomal abnormalities or gene mutations.

¹⁰ NHS Choices. (2016) 'Attention deficit hyperactivity disorder (ADHD)' <http://www.nhs.uk/Conditions/attention-deficit-hyperactivity-disorder/Pages/Introduction.aspx>. Accessed 05/01/2016.

¹¹ NHS Choices. Autism spectrum disorder (ASD). Available at: <http://www.nhs.uk/conditions/Autistic-spectrum-disorder/Pages/Introduction.aspx>. Accessed 05/19/2016.

¹² 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.

¹³ For further information see NHS Choices (2014) 'Phenylketonuria' <http://www.nhs.uk/conditions/Phenylketonuria/Pages/Introduction.aspx>

Mother and baby having different blood types

When a mother's blood type is different to the baby's, there is risk that the mother's body forms antibodies that can attack the baby's blood causing disabilities, such as cerebral palsy and deafness.

Infectious diseases suffered by mothers and children

A number of viral and sexual infectious diseases suffered by mothers during pregnancy, including measles and HIV, can cross the placental barrier and cause disabilities. Diseases suffered by children in early childhood, such as meningitis and measles can also cause disability.

Premature birth and/or low birth weight babies

Babies who are born early and/or have a low birth weight have approximately a 20% chance of having a disability. Premature birth and low birth weight can be caused by maternal lifestyle choices, for example smoking or poor nutrition. However, for a majority of women who have preterm births, the causes are unclear.

Foetuses being exposed to drugs and/or radiation

Prescription drugs, environmental pollutants and radiation can cause birth defects.

Poor maternal nutrition

Deficiencies in key vitamins and minerals can lead to disabilities, for example hydrocephalus and spina bifida¹⁴.

Maternal use of drugs and alcohol

Excessive use of recreational drugs and alcohol amongst mothers during pregnancy can lead to developmental problems and/or disabilities in the child. Maternal smoking - smoking restricts the oxygen supply to the baby raising the risk of low-birth weight and premature birth, both of which increase the probability of a child being disabled.

Parental age

Older and younger parents are more at risk of complications that can result in childhood disability. Those under 20 are more at risk of poor nutrition and poor placental transfer of food and oxygen, whereas those who have children later are more likely to suffer from chromosomal abnormalities.

Socio-economic status

Children and young people with disabilities are more likely to live in households in lower socio-economic positions and exposed to poverty. They are more likely to experience recurrent poverty, to become poor and less likely to escape poverty. Children and young

¹⁴ Taken from Lancashire County Council ' *Disability of children and young people*' <http://www.lancashire.gov.uk/lancashire-insight/health-and-care/disability/disability-in-children-and-young-people.aspx> Accessed 05/12/2016

people from less advantaged socio-economic backgrounds tend to be disproportionately represented amongst those with disabilities. These households may be more vulnerable to lifestyle factors that can contribute to disability. In childhood these children, like others amongst their socio-economic group will be at risk of poor nutrition, greater rates of injury and poorer mental health. The additional costs in meeting the needs of a child with disability can also itself be a major contributor to material poverty¹⁵.

Physical injury

Injury to the mother's abdomen during pregnancy can result in disabilities when the child is born. Accidents and injuries suffered by children can also result in disability¹⁶.

Epidemiology

Understanding the epidemiology of disability is complicated by:

- 1) differences in the definitions of disability used when prevalence estimates are calculated
- 2) in the methodologies used to estimate prevalence.

As a result, there is marked variation in the estimated number of children living with disability when different estimates of prevalence are used. For example:

- A survey of directors of children's services carried out by the Thomas Coram Research Unit estimated that the prevalence of disability in children was 3.0%-5.4%¹⁷. If these figures were applied to the Kent population of children and young people aged 0-24 years this would equate to 13,620-24,516 children and young people living with disability.
- In contrast a secondary analysis of the Family Resource Survey (2004/05) found the prevalence of disability in children to be 7.0%¹⁸, which would equate to 31,780 children living with disability in Kent.

In addition, these prevalence estimates do not take into account differences in the age structure of the population or the distribution of other factors associated with disability rates, such as deprivation and premature birth rates.

¹⁵ PHE (2015) 'The determinants of health inequities experienced by children with learning disabilities' http://www.improvinghealthandlives.org.uk/securefiles/160826_1222//Determinants%20of%20Child%20Health%20Inequalities.pdf Accessed 05/12/2016

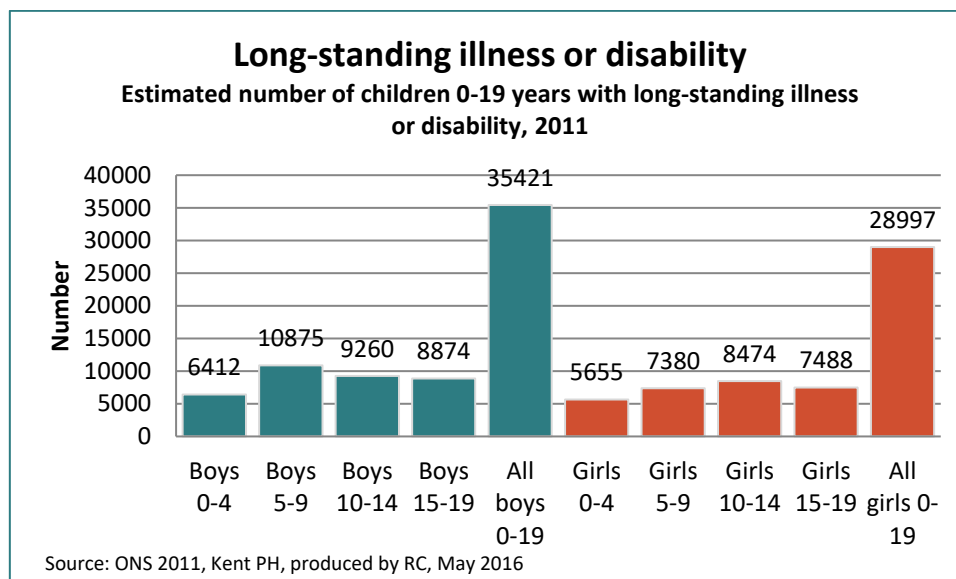
¹⁶ Taken from Surrey County Council (2011) 'JSNA chapter Children with Disabilities' <http://www.surreyi.gov.uk/Resource.aspx?ResourceID=665&cookieCheck=true&JScript=1> Accessed 05/12/2016

¹⁷ Thomas Coram Research Unit & Institute of Education (2008). 'Disabled Children: Numbers, Characteristics and Local Service Provision' https://www.researchgate.net/publication/256840534_Disabled_children_Numbers_characteristics_and_local_service_provision Accessed 01/12/2016

¹⁸ 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 Paediatrics* Apr 16;10:21-2431-10-21.

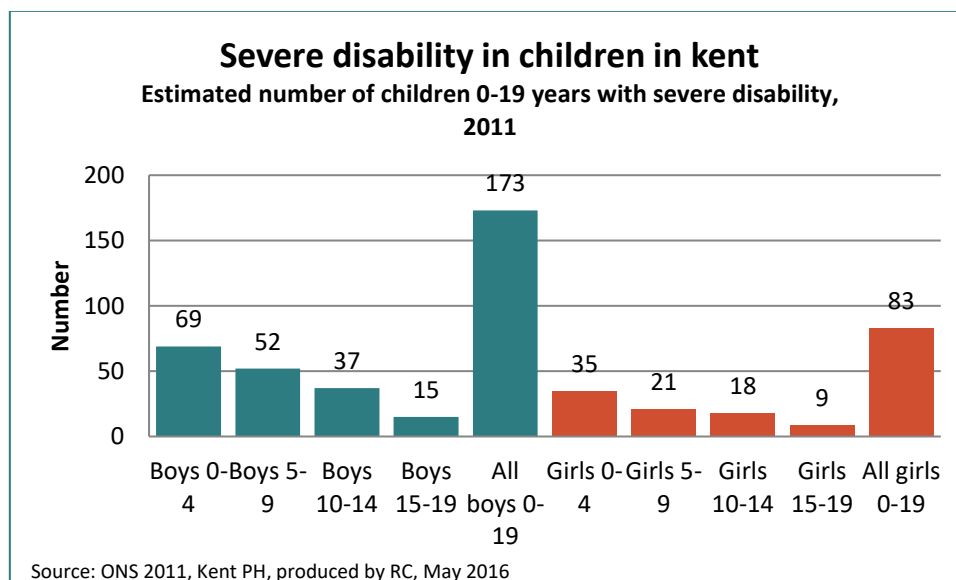
Given the complexity of accurately estimating the true level of need of children with disability in a local population, the following figures should be interpreted with caution.

Figure 2: Prevalence of long-standing illness and disability in children and young people in Kent



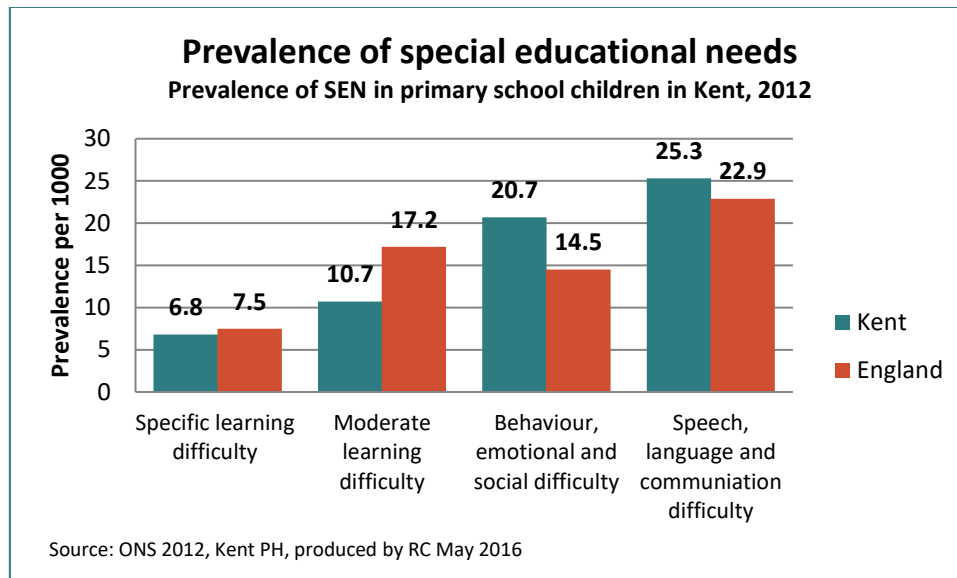
The figure above shows the expected number of children aged 0-19 years in Kent with long-standing illness or disability. At all ages the number of boys with long-term illness or disability is higher than the number of girls.

Figure 3: Children with a severe disability



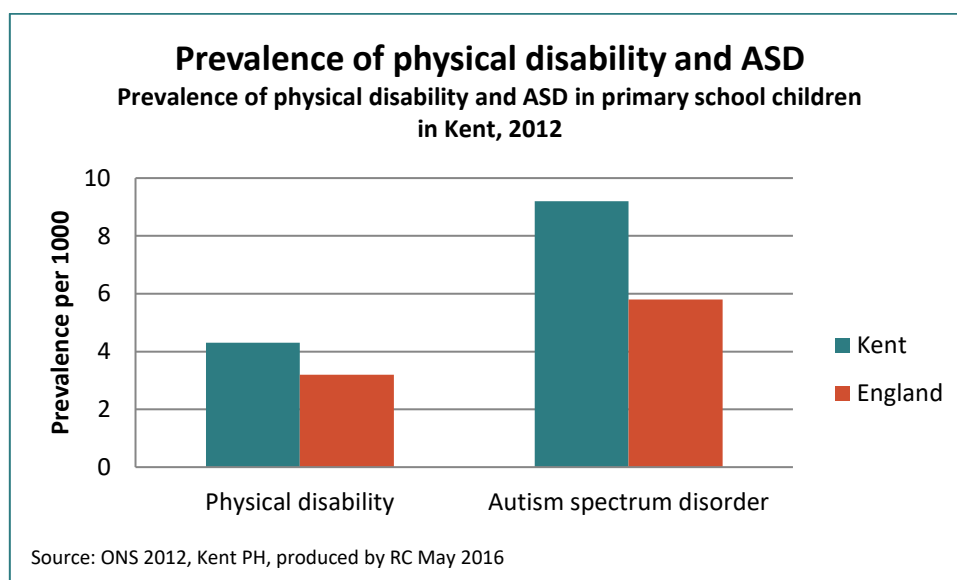
The figure above shows the expected number of children aged 0-19 years in Kent with a severe disability. The number of boys with a severe disability is higher than the number of girls at all ages. The number of children with severe disability decreases with age due to significant mortality in children with severe disability.

Figure 4: Prevalence of special educational needs in children and young people in Kent - Primary Schools



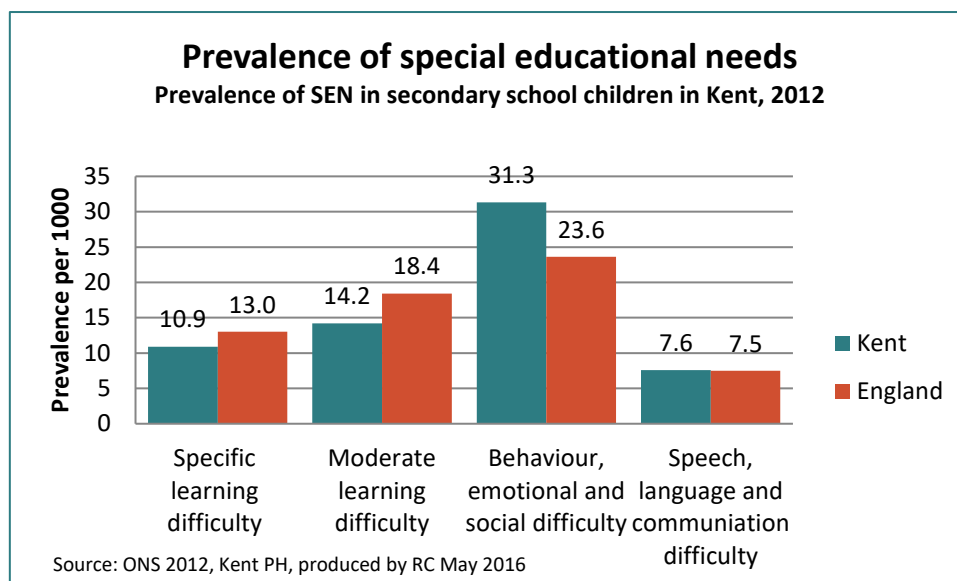
The figure above shows the estimated prevalence of special educational needs in primary schools in Kent 2012. The prevalence of specific and moderate learning difficulty was lower in Kent than in England, while the prevalence of behavioural, emotional and social difficulty, and speech, language and communication difficulty was higher. The prevalence of severe learning difficulty in Kent at 1.20 per 1000, and of profound and multiple learning difficulty in Kent at 0.5 per 1000, was similar to levels seen nationally.

Figure 5: Prevalence of physical disability and ASD in children and young people in Kent - Primary Schools



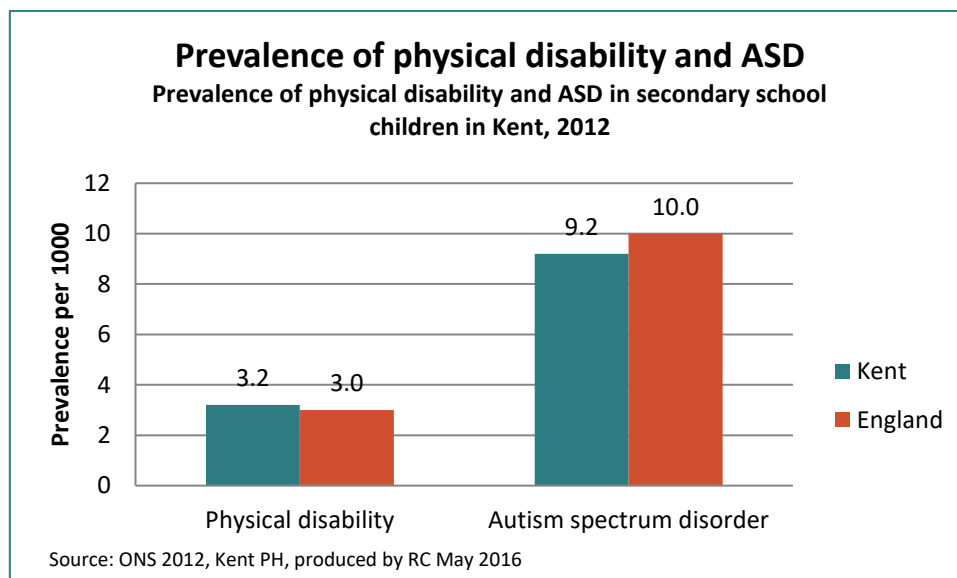
The prevalence of physical disability per 1000 was higher in Kent at 4.30 per 1000, than in England at 3.20 per 1000. The prevalence of ASD was higher in Kent at 9.2 per 1000, than in England at 5.8 per 1000.

Figure 6: Secondary schools



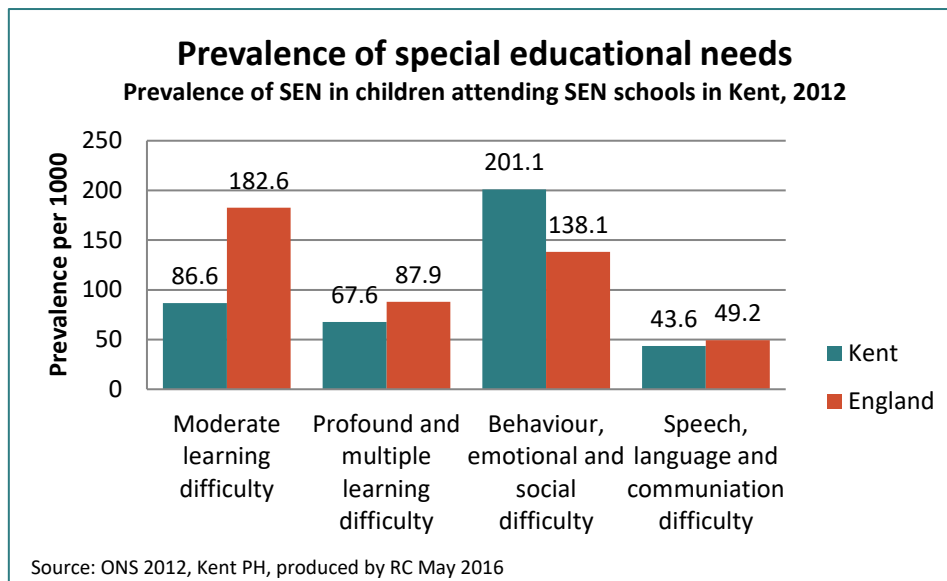
The figure above shows that the prevalence of specific and moderate learning difficulties was lower in secondary school children Kent than in England, while the prevalence of behavioural, emotional and social difficulty, and speech, language and communication difficulty was higher. The prevalence of severe learning difficulty and profound and multiple difficulty in secondary school children was similar in Kent and England.

Figure 7: Secondary schools



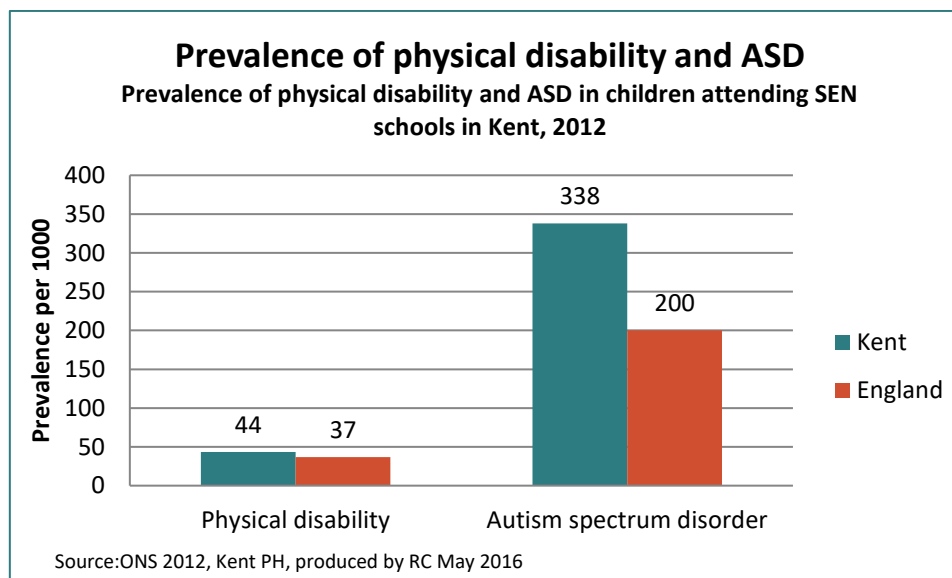
The prevalence of physical disability in Kent and England was similar. The prevalence of ASD in secondary school children in Kent was slightly lower than that noted in England, which is a reverse of the pattern seen in primary school children demonstrated above.

Figure 8: Prevalence of special educational needs schools



The figure above demonstrates the prevalence of SEN in children attending SEN schools in Kent and England. 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 9: 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.

Children and young people aged 0-24 years claiming Disability Living Allowance

The number of children and young people claiming Disability Living Allowance (DLA) gives some indication of the level of need in Kent. However, it should be noted that this will not include those people who have not had a diagnosis of disability or who have had an application for DLA turned down.

Projecting the number of children living with disability in Kent

Owing to the difficulties interpreting the various estimates of prevalence for disability as a general term, estimates of the number of children affected by specific types of disability have been attempted.

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

The table above provides the projected changes in the number of young people living with a learning disability in Kent 2013-2033. A 12.4% increase is anticipated. There is some variation between the Kent and the CCG values. This can be accounted for by anticipated changes in the population size and age structure.

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

Sight impairment in children is strongly linked to genetic factors or premature / low birth weight. In addition, some children who are particularly risk of developing sight problems are those with:

- sensorineural hearing impairment
- neuro developmental problems (including Down's)
- a family history of childhood onset ophthalmic disorder e.g. retinoblastoma¹⁹.

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 largest cause of sight impairment is brain disorder, of which cerebral palsy and cerebral visual impairment are the most common.

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.

Continence

There is a high prevalence of continence in children with disabilities. Continence may be temporary or permanent, and may change with their developmental stage and the trajectory of their health needs.

- half of all children with a physical disability may have continence problems
- there is a clear association between severity of disability and incontinence.

The risk of underlying bladder and bowel comorbidities in children and young people with additional needs is often not recognised, resulting in potential long-term damage. The importance of a comprehensive assessment is highlighted in 'Understanding bowel and bladder comorbidities in children and young people with additional needs – the importance of assessment'^{20 21}.

¹⁹ KPHO (2014) ' *Sensory Health Needs Assessment*'
http://www.kpho.org.uk/data/assets/pdf_file/0018/43551/Eye-Health-Needs-Assessment-Final-Version-Sept-2014.pdf page 37

²⁰ CHIMAT (2016) ' *Continence Health Needs Assessment*'
<http://atlas.chimat.org.uk/IAS/profiles/profile?profileId=45&geoTypeId=> Accessed 05/12/16

Childhood obesity²²

Children with disabilities are more likely to be overweight and obese. The risk increases with age. This increased risk is associated with lifestyle factors like nutrition, being sedentary, limited mobility parental attitude and socio-economic status²³.

Emotional and mental health

Children and young people with learning disabilities are more likely to experience mental health problems, with prevalence rates up to 40% and higher rates observed for those with severe learning disabilities²⁴.

Table 2: Estimated number of children with learning disability and mental health problem by age²⁵

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

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

The table above provides estimates of children and young people in Kent with learning disabilities.

Bullying is a feature in the lives of many disabled children²⁶ and is associated with the development of poor mental health problems.

²¹ PromoCon (2014) 'Understanding bowel and bladder comorbidities in children and young people with additional needs – the importance of assessment' <http://docplayer.net/11699196-Understanding-bladder-bowel-comorbidities-in-children-young-people-with-additional-needs-the-importance-of-assessment.html>

²² PHE http://www.noo.org.uk/securefiles/160826_1403//obesity%20and%20disability%20-%20child%20and%20young%20people%2019%2002%2014.pdf

²³ PHE http://www.noo.org.uk/securefiles/160826_1403//obesity%20and%20disability%20-%20child%20and%20young%20people%2019%2002%2014.pdf

²⁴ KPHO (2014) ' CAMHS Health Needs Assessment' <http://www.kpho.org.uk/health-intelligence/population-groups/children-and-young-people/kent-child-and-adolescent-mental-health-needs-assessment> Accessed 05/12/2016

²⁵ CHIMAT (2016) ' CAMHS Health Needs Assessment' <http://atlas.chimat.org.uk/IAS/profiles/profile?profileId=34&geoTypeId=> Accessed 05/12/2016

²⁶ NSPCC (2014) ' Right Safe' <https://www.nspcc.org.uk/globalassets/documents/research-reports/right-safe-disabled-children-abuse-report.pdf> Accessed 26/08/2016

Substance Misuse

Young people with disabilities are at risk of problematic substance misuse. Reasons suggested for this include the difficulty in participating in school culture, having communication issues which leads to drug use to deal with distress, frustration, isolation, exclusion and bullying. They may experience social pressure and drugs may be used as a means of 'fitting in' and gaining acceptance. Mental health problems and poverty may increase the risk of disabled young people using substances. Communication difficulties and the lack of accessible information may aggravate drug problems and inhibit help-seeking for some disabled young people. Young people may also use substances as a form of self-medication to alleviate the symptoms of long-term illnesses²⁷.

Sexual health

Children and young people with disabilities are vulnerable to poor sexual health and to sexual exploitation. Parents and carers of these children may need additional information to support their young people's transition into puberty and adulthood given their additional needs.

Issues of availability and access exist for children and young people with learning disabilities in relation to sex and relationships education (RSE) and sexual health services.

Findings from research conducted by Leeds University over a three year period (2007 -2017) with young people with learning disabilities identified that:

- 'several of the young people thought gay sex was illegal in contrast, several didn't realise that the police investigate cases of sexual abuse
- others were unaware that sex could lead to pregnancy
- some had little or no understanding of contraception
- few knew that pregnancy would last nine months.

Equally, parents and teachers revealed further issues for the young people with learning disabilities:

- some were frightened and confused by puberty
- girls were unprepared for menstruation - and unable to deal with it when it happened
- a number of the young men had a tendency to masturbate in public
- some of the young people were unable to handle the emotional side of relationships - including a girl who stalked a former boyfriend
- a misunderstanding led to one young man being arrested for indecency.⁸

The recommendations of this study were:

²⁷ Addaction and Young Minds '*Childhood adversity, substance misuse and young people's mental health*' <https://youngminds.org.uk/media/1547/ym-addaction-briefing.pdf> Accessed 30/07/2018

- professionals not listening to people with learning disabilities or not taking them seriously
- young people with learning disabilities having nowhere to go to meet their friends
- not enough accessible information about relationships and sex²⁸.

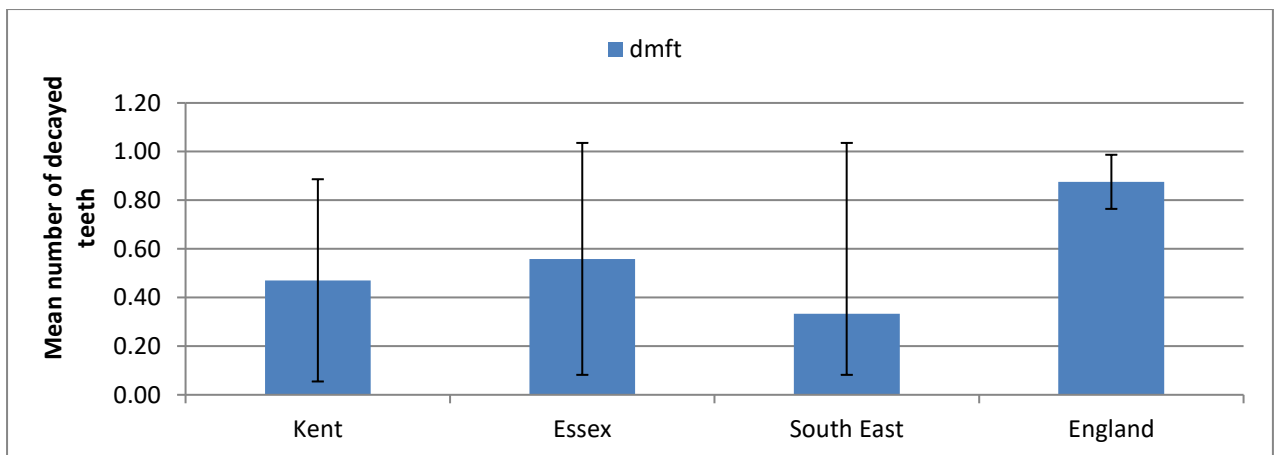
Sexual, physical and emotional abuse

Disabled children are at significantly greater risk of physical, sexual and emotional abuse and neglect than non-disabled children, with children with conduct disorders/ behavioural issues being at greatest risk. Children in residential settings are particularly vulnerable. Children with disabilities may delay disclosing their abuse²⁹. Exposure to abuse and adversity in childhood increases the likelihood of ill-health in adulthood including mental ill-health and health harming behaviours like substance misuse.

Oral health:

In 2014, a survey was conducted of oral health of five and 12 year olds in special school settings in England. Data for Kent five year olds indicated that rates of dental decay, rates of severity of tooth decay (expressed in terms of the mean number of decayed teeth) in this group was lower in Kent (0.47) than in Essex (0.56) and in England (0.88) and higher than decay severity in the South East (0.33) although not statistically, significant in either direction.

Figure 10: Severity of decay in five-year-olds in special support schools in Kent, 2014



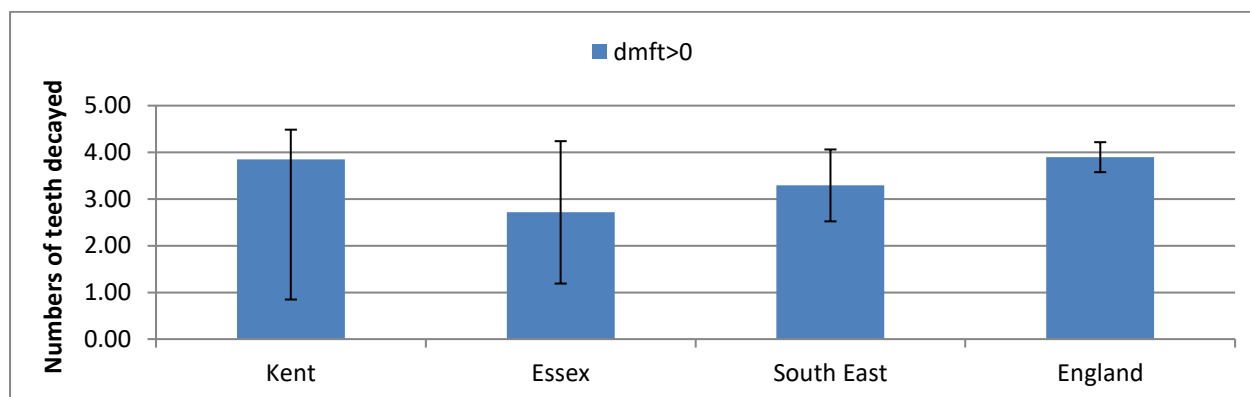
Source: PHE

²⁸ University of Leeds/Change (2010) 'Talking about Sex and Relationships' <http://disability-studies.leeds.ac.uk/files/library/change-final-report-read-copy.pdf> Accessed 05/12/2016

²⁹ NSPCC (2014) 'Right Safe' <https://www.nspcc.org.uk/globalassets/documents/research-reports/right-safe-disabled-children-abuse-report.pdf> accessed 26/08/2016

Where five-year-olds in special support groups had decay, the average number of teeth decayed per child in Kent was four teeth (Figure 10) which is the same as England. Kent had higher numbers of teeth decayed than Essex and the South East where the average is three per child, though this was not statistically significant.

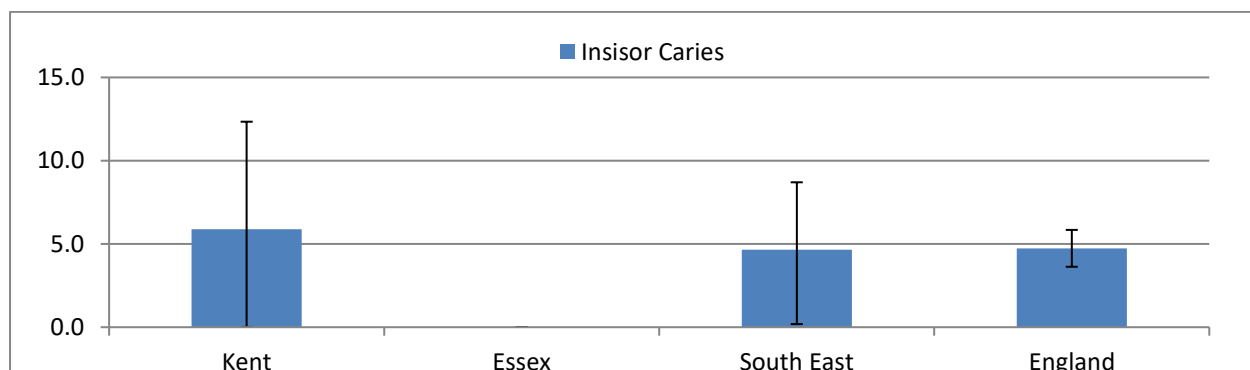
Figure 11: Decay numbers in five-year-olds in special support schools in Kent, 2014



Source: PHE

Kent had higher levels of incisor caries in five-year-old children in special support schools at an average of six per child. This can be compared to no evidence of incisor caries in Essex children and five per child in the South East and England though these differences are not statistically significant.

Figure 12: Insisor decay in five-year-olds in special support schools in Kent, 2014

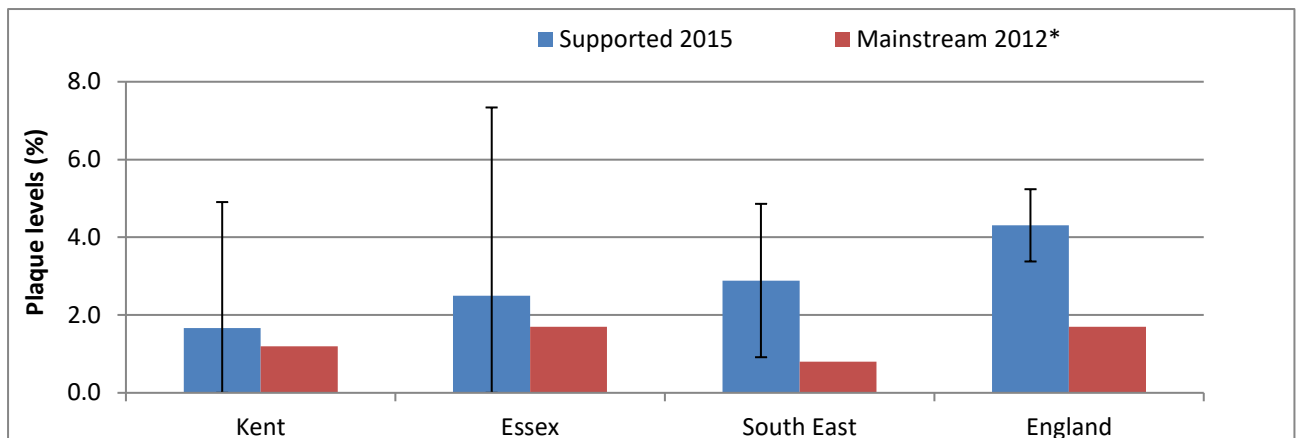


Source: PHE

Plaque levels are illustrative of oral hygiene and its effectiveness, and when present often symptomatic of non-brushing, or an incorrect brushing technique. Kent had lower (1.7%) levels of visible plaque than Essex (2.5%) the South East (2.9%) and England (4.3%) although this was not statistically significant.

In addition, it should be noted that plaque levels were higher in five-year-olds in supported educational environments than in mainstream school in Kent, Essex, the South East and England when comparing surveys published in 2012 (Mainstream) and 2014 (Supported). In Kent five-year-olds, in supported education, scores were higher (1.7%) on plaque levels than those in Mainstream* education (1.2%) though significance could not be established.

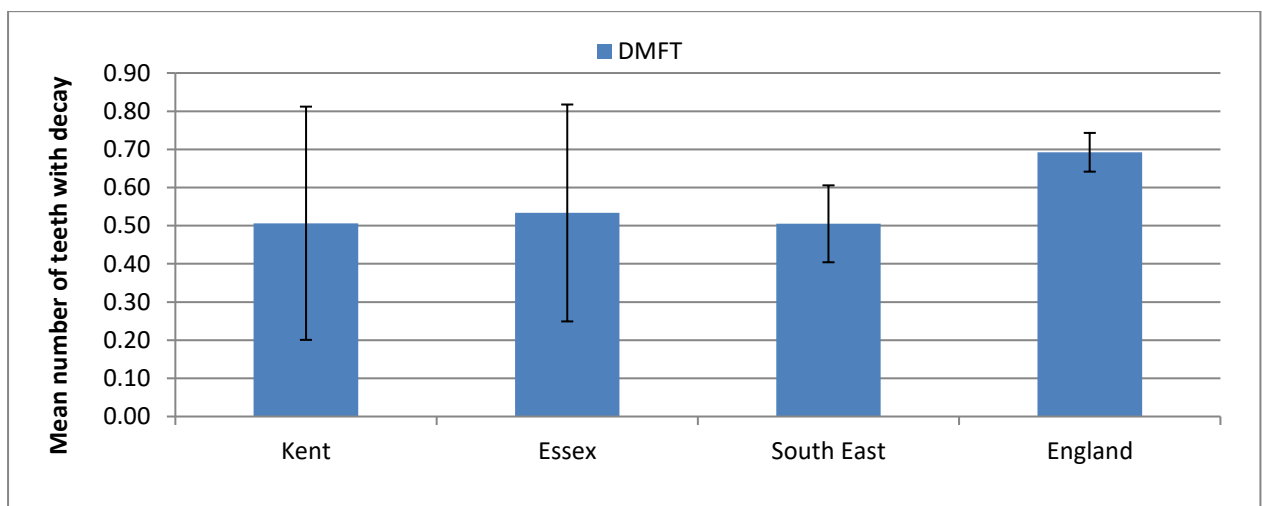
Figure 13: Plaque levels in Supported and Mainstream educated 5-year-olds, 2012 and 2014



Source: PHE *confidence intervals not available

Severity of tooth decay was lower in Kent (0.51) 12-year-olds than in Essex (0.53) and in England (0.69) and higher than decay severity in the South East (0.50) though not statistically significant in either direction.

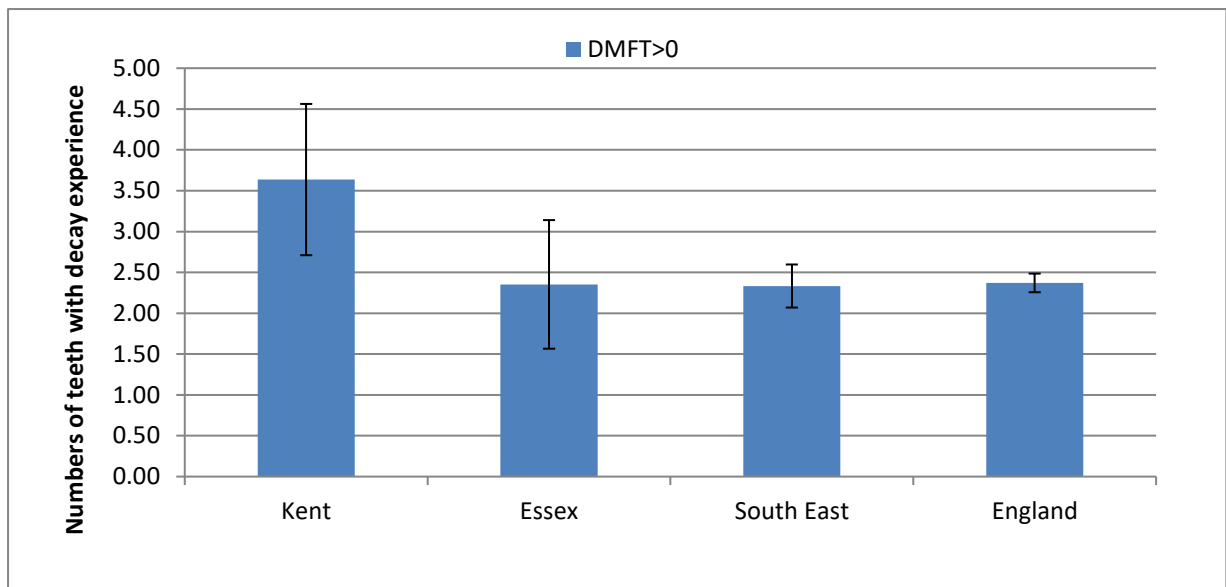
Figure 14: Severity of decay in 12-year-olds at Kent County level, 2014



Source: PHE

Where 12-year-olds have decay, the average number of teeth decayed per child in Kent was 3.6; higher than in Essex (2.35) and statistically, significantly higher than in the South East (2.33) and England (2.37).

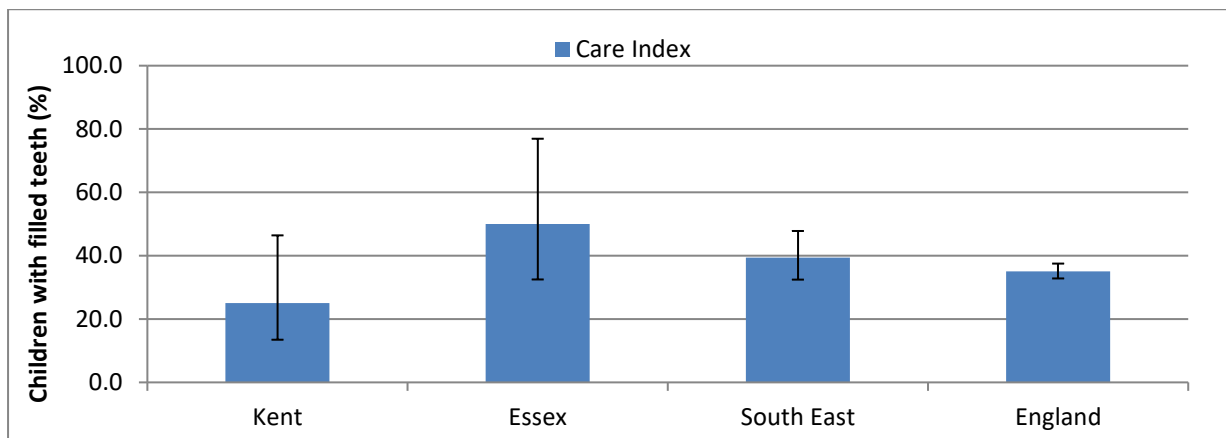
Figure 15: Severity of decay in 12-year-olds in Supported Education in Kent, 2014



Source: PHE, 2015

Management of decay by means of fillings (Figure 15) was lower in Kent (25%) 12-year-olds than in Essex (50%) the South East (40%) and England (35%) although the difference was not statistically significant.

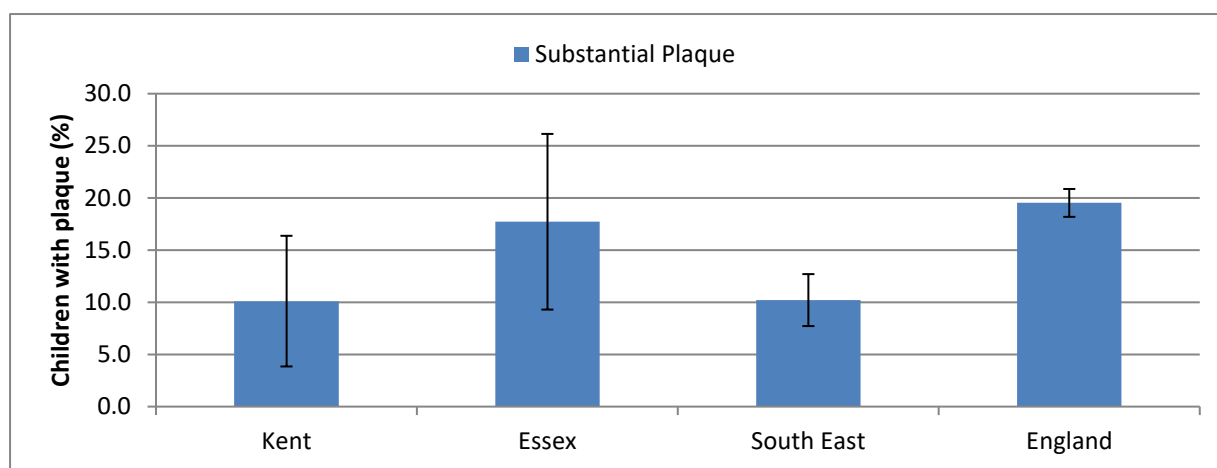
Figure 16: Management of decay in 12-year-olds in Supported Education in Kent, 2014



Source: PHE

Levels of “substantial plaque” were lower in 12-year-olds in Supported Education in Kent (10%). Plaque levels were similar to the South East but lower than Essex (18%) and statistically, significantly lower than England (19%).

Figure 17: Percentage of 12-year-olds in Supported Education in Kent with plaque, 2014



Source: PHE

Children in Care³⁰

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). The increase was particularly observed in the ‘behaviour’ and ‘learning disabilities’ categories. 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.

The predominant disabilities amongst Kent’s children in care are Autistic Spectrum Conditions and behaviour and learning issues. Children over the age of 10 are particularly represented in these needs and are some of the most difficult children to place.

Young people engaged with the Youth Justice System (YJS)

Young offenders are a group of young people who are subject to significant disadvantage and disproportionate levels of health need. They have a high prevalence of mental and physical health conditions, and health harming behaviours. It is not surprising that there is a significant level of comorbidity amongst young offenders. This includes dual diagnosis of substance misuse and mental ill health and the co-existence of conduct disorders and depression and / or attention deficit hyperactivity disorder (ADHD).

³⁰ KPHO (2015) ‘ Children in Care Needs Assessment’
http://www.kpho.org.uk/data/assets/pdf_file/0007/43567/Children-in-care-needs-assessment.pdf

Those young people with ADHD may also have a generalised or specific learning disability. Hughes identifies 'This may have a marked impact on how such conditions are experienced and subsequently may complicate both the assessment and management process'³¹.

It is understood that young people who offend have 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 disability³². 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 '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'³³.

³¹ 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

Ryan & Tunnard (2011) 'Evidence about the health and well-being needs of children and young people in contact with the youth justice system' <http://www.chimat.org.uk/resource/view.aspx?RID=111768> Accessed 22/12/2016

³² Chitsabesan P (2006) 'Mental Health provision for young offenders ; service use and cost' *British Journal of Psychiatry* 188 (541-546), 0007-1250,1472-1465

³³ 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

Service Delivery

In addition to the universal services including preventative health care which are required to be equally accessible to children and young people with disabilities, there are specific support services available to children with disabilities across health and social care.

National reports and local inspections in Kent have identified inequality of service delivery and access across Kent.

Preventative Health Care

Preventative healthcare for children includes screening, immunisations and tests which are recommended by the National Screening Committee and laid out in the Healthy Child Programme.

Emmerson (2015) analysis of the Millennium Cohort found that children with learning disabilities in the UK were less likely than their non-disabled peers to access preventative health interventions on 15 (65%) of 23 indicators³⁴.

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 and as a result of advances in healthcare which have reduced childhood mortality. It is estimated that children and young people with disabilities will increasingly have complex health needs. Healthcare services will be required to respond in ways which are developmentally appropriate and support young people to effectively transition into adulthood and wherever possible, to independent living.

Findings and recommendations are listed in relation to commissioning, to information and to governance.

Commissioning

Commissioners take action to

- Prevent and mitigate against risks which may cause children and young people to be disabled
- Address in equities 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.

³⁴ Emmerson E (2015) (2015) 'The determinants of health inequities experienced by children with learning Disabilities' http://www.improvinghealthandlives.org.uk/securefiles/160826_1222//Determinants%20of%20Child%20Health%20Inequalities.pdf Accessed 05/12/2016

Preventing and Mitigating Risk

- 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 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 children's community nursing,
- Ensure access of those young people with learning disabilities who are registered aged 14 plus to a developmentally appropriate annual health review.

Address inequities and insufficiencies of health, social care and education provision across Kent

- Map provision and utilisation of services for children and young with disabilities in Kent 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
 - Continence 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 PSHE for young people with learning disabilities and information and support for their parents and carers
 - Access to therapies including SALT

Identify opportunities for developing holistic assessment of needs and health promotion across the life course including the following:

- 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

Ensure care is well coordinated around the needs of the child and family

- Progress the utilisation of Health, Education and Care (EHC) Plans
- Ensure that EHC are shared and care coordinated with CIC plans and YOS Care Plans

Seek feedback from parents and carers and children and young people to ensure the best possible outcomes for children and young people

- Ensure the views of children, young people and parents and carers are systematically collected and informs service development

Informatics

- Accurate recording of childhood disabilities problematic is, 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 CYPHS 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 commissioning, embedding them within contracts and improving data compliance and quality.
- Progress the flow of data to the Kent Integrated Dataset.

Governance

- Health and wellbeing Board 0-25 , as signatories of the 'Charter for Disabled Children'³⁵ need to be aware of and actively exercise their oversight of the population of children and young people with SEND and complex needs as set out in https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/357447/DH_HWB_children_s_guidance.pdf

³⁵ Council for Disabled Children (ND) 'Charter for Disabled Children'
<http://councilfordisabledchildren.org.uk/our-work/social-care/policy/disabled-childrens-charter>

Bibliography

Addaction and Young Minds 'Childhood adversity, substance misuse and young people's mental health' <https://youngminds.org.uk/media/1547/ym-addaction-briefing.pdf> Accessed 30/07/2018

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.

BMA Board of Science (2013)' *Growing up in the UK*'. <https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/child-health/growing-up-in-the-uk> Accessed 02/12/2016

CHIMAT (2016) '*Continence Health Needs Assessment*'
<http://atlas.chimat.org.uk/IAS/profiles/profile?profileId=45&geoTypeId=> Accessed 05/12/16

Chitsabesan P (2006) 'Mental Health provision for young offenders ; service use and cost' *British Journal of Psychiatry* 188 (541-546), 0007-1250,1472-1465

Council for Disabled Children (ND) '*Charter for Disabled Children*'
<http://councilfordisabledchildren.org.uk/our-work/social-care/policy/disabled-childrens-charter>

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

Emerson E (2015)' *The determinants of health inequities experienced by children with learning disabilities*'
https://www.basw.co.uk/system/files/resources/basw_24424-2_0.pdf - Accessed 05/12/2016

Hughes et al (2012)'*Nobody made the connection: the prevalence of neuro disability in young people who offend*'
https://yjlc.uk/wp-content/uploads/2015/03/Neurodisability_Report_FINAL_UPDATED_01_11_12.pdf - Accessed 22/12/2016

Institute of Health Equity (2010) '*Fair society, healthy lives*'
<http://www.instituteoftheequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review/fair-society-healthy-lives-full-report-pdf.pdf> - Accessed 05/12/2016

KPHO (2014) '*Sensory Health Needs Assessment*'

http://www.kpho.org.uk/_data/assets/pdf_file/0018/43551/Eye-Health-Needs-Assessment-Final-Version-Sept-2014.pdf

KPHO (2015) '*Kent Learning Disability Health Checks*'

http://www.kpho.org.uk/_data/assets/pdf_file/0014/53411/Learning-Disabilities-Annual-Health-Checks.pdf

KPHO (2015) '*Children in Care Needs Assessment*'

http://www.kpho.org.uk/_data/assets/pdf_file/0007/43567/Children-in-care-needs-assessment.pdf

Lancashire County Council '*Disability of children and young people*'

<http://www.lancashire.gov.uk/lancashire-insight/health-and-care/disability/disability-in-children-and-young-people.aspx> - Accessed 05/12/2016

NHS Choices (2016) '*Developmental coordination disorder (dyspraxia) in children*'.

[http://www.nhs.uk/conditions/Dyspraxia-\(childhood\)/Pages/Introduction.aspx](http://www.nhs.uk/conditions/Dyspraxia-(childhood)/Pages/Introduction.aspx) Accessed 05/19/ 2016.

NHS Choices. (2016) '*Attention deficit hyperactivity disorder (ADHD)*'

<http://www.nhs.uk/Conditions/attention-deficit-hyperactivity-disorder/Pages/Introduction.aspx>. Accessed 05/01/2016

NSPCC (2014) '*Right Safe*'

<https://www.nspcc.org.uk/globalassets/documents/research-reports/right-safe-disabled-children-abuse-report.pdf> - accessed 26/08/2016

University of Leeds/Change (2010) '*Talking about Sex and Relationships*'

<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/change-final-report-read-copy.pdf> - accessed 05/12/2016

Ryan & Tunnard (2011) '*Evidence about the health and well-being needs of children and young people in contact with the youth justice system*'

<http://www.chimat.org.uk/resource/view.aspx?RID=111768> Accessed 22/12/2016

Surrey County Council (2011) '*JSNA chapter Children with Disabilities*'

<http://www.surreyi.gov.uk/Resource.aspx?ResourceID=665&cookieCheck=true&JScript=1>
Accessed 05/12/2016

Thomas Coram Research Unit and Institute of Education (2008). ' *Disabled Children: Numbers, Characteristics and Local Service Provision*'
https://www.researchgate.net/publication/256840534_Disabled_children_Numbers_characteristics_and_local_service_provision Accessed 01/12/2016

University of Leeds/Change (2010) ' *Talking about Sex and Relationships*'
<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/change-final-report-read-copy.pdf> - Accessed 05/12/2016

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.

World Health Organisation.(2002) ' *Towards a common language for functioning, disability and health*'
<http://www.who.int/classifications/icf/icfbeginnersguide.pdf?ua=1> - Accessed 11/06/2016.

Kent Learning Disability Health Checks (2015)
http://www.kpho.org.uk/_data/assets/pdf_file/0014/53411/Learning-Disabilities-Annual-Health-Checks.pdf

KPHO (2014) ' *Sensory Health Needs Assessment*'
http://www.kpho.org.uk/_data/assets/pdf_file/0018/43551/Eye-Health-Needs-Assessment-Final-Version-Sept-2014.pdf - page 37