Topic information	
Topic title	Children and Young People Special Educational Need and Disability
Topic owner	Helene Denness
Topic author(s)	Russell Wiseman, Helene Denness and Jean Robinson
Topic quality reviewed	30/11/2016
Topic endorsed by	Special Educational Needs Board
Current version	2016/17
Replaces version	2010
Linked JSNA topics	Adults with Learning Disability Pregnancy

Executive summary

Introduction

This chapter considers the health and education needs of children and young people, 0 25 years, with special educational needs and disabilities who live in Nottingham City. The needs of adults with disabilities are outlined in other chapters.

Children and young people with special educational needs and disabilities are a broad and diverse group and include individuals with complex needs requiring multi level support as well as those who require substantially less input (ChiMat 2016).

Special educational needs are legally defined:

> "Children who have learning difficulties or disabilities that make it significantly harder for them to learn or access education than most other children of their age" (Department for Education 2014).

The definition of special educational needs is a broad one covering a wide range of need including behavioural, emotional and social difficulties, autistic spectrum disorders and specific learning difficulties such as dyslexia.

A person is disabled if he or she has a "…physical or mental impairment that has a 'substantial' and long-term' negative effect on his or her ability to do normal daily activities" (Equality Act 2010).

Children and young people who have special educational needs (SEN) experience significant barriers to learning but do not necessarily have a disability. Children and young people with disabling conditions do not necessarily have SEN, however, there is a significant overlap between disabled children and young people and those with SEN. Porter et al (2008) estimate that approximately three-quarters of 'disabled' children are also identified as SEN.

The number of disabled children (0-18) in England is estimated to be between 288,000 and 513,000 (Porter et al 2008). The mean percentage of disabled children in English local authorities has likewise been estimated to be between 3.0% and 5.4%. This estimate is based on a 2008 study which has not been repeated and thus may underestimate 'true' numbers given demographic changes in the population such as an increase in neonatal survivors and inward migration of children with disabilities.

A number of factors, including gender, ethnicity, socio-economic disadvantage, parental behaviour and communicable disease, appear related to the prevalence of special educational needs and disabilities but the mechanism underpinning these links are not always well understood.

Of all the childhood disabilities, neurodevelopmental conditions including autism, ADHD, developmental disorders and cerebral palsy, are the most common (Chief Medical Officer's Report 2012). Many of these children and young people experience a number of impairments and co morbidities which, in conjunction with restrictions and barriers to participation, result in complex medical, educational and social support needs.

Local estimates of the numbers of children with SEN and disability are based on various routine data sources such as the Statistical First Returns to the Department for Education, Disability Living Allowance statistics and local figures of numbers accessing a range of children's services. These sources suggest that in 2015 there were approximately 3,500 – 4,000 children and young people, aged under 25 years, in Nottingham with disabilities.

Of these, approximately a 1000 children/young people have severe, complex and/or lifelong disabilities. This figure is based on a data collection from 2009 which has not been repeated. Local intelligence suggests this may be an underestimation of the actual number thus conclusions should be treated with caution. In the same time period 7,500 children were identified as having special educational needs, of which a proportion also had a disability.

Disabled children and young people can lead full and fulfilling lives but for many, disability is associated with limited development and social participation, poor educational, health and employment outcomes (Department for Work and Pensions 2013). Nottingham City's aspiration for children and young people with special educational needs and disabilities, like all children and young people, is that they achieve well in their early years, at school and in college, and lead happy and fulfilled lives.

Local work undertaken has increased the proportion of young people in education and training and increased opportunities for young people to participate in activities in their local communities.

Unmet need and gaps

- Feedback from parents/carers and professionals suggests that there are significant challenges in accessing Speech and Language Therapy (SALT) in Nottingham. Data suggests that there are more children and young people

with autism in Nottingham than the England average; autistic children are particularly likely to need SALT.

- Feedback from parents suggests that there is a lack of information regarding SEND provision. It is unclear whether lack of use relates to lack of awareness of the SEND Local Offer website or the functionality of the website itself.
- Evidenced based interventions early in life can improve outcome for disabled children yet not all children in Nottingham access early support services.
- Not all children with SEND are vaccinated as recommended which makes them vulnerable to infectious diseases which can be more serious for those who also have physical disabilities. In addition, some disabilities are associated with vaccine preventable diseases such as birth defects due to congenital rubella syndrome or encephalitis following measles.
- Local intelligence suggests that children and young people with SEND sometimes miss out on health promotion interventions such as school-based sessions on sex and relationships and/or smoking, drugs and alcohol even though these sessions could be adapted to meet their needs.
- Parents report that SEND support varies from school to school. Whilst many schools are committed to supporting children and young people with SEND parents reporting that some school staff lack appropriate knowledge and skills which hinders their ability to fulfil their potential.
- The range of short breaks available to disabled children and young people is limited and is not always sufficiently tailored to meet individual needs.
- Literature suggests that there is an under representation of some ethnic minorities in diagnosis of SEND e.g. autism. It is unclear whether this is due to lack of awareness within these communities, stigma around disability or professionals not diagnosing in these groups.
- Consanguinity is a significant risk-factor for some disability. It is unclear whether more action could be taken to highlight the risk to relevant communities.
- The process of assessment can lead to a focus on what children and young people with SEND can't do rather than what they can achieve, particularly, when they have the support of their family and community.
- Children, young people and families report feeling isolated in part as they struggle to access activities in their local community.
- There is less transition support for young people with SEND who do not have an EHCP/statement and/or don't meet social care thresholds for support. For these young people the support is managed by the school without little additional support from outside agencies. This does not meet NICE guidance on transition.

- There are low levels of employment for people with learning disabilities. It is unclear why Nottingham has a significantly lower proportion of people with learning disabilities in employment than the England average. Incomplete tracking of young people post-19 is a barrier to understanding which strategies are successful in supporting young people with learning disabilities into work.

- Whilst considerable action has been taken people with learning disability are still in healthcare institutions as adults. This is unacceptable.

Recommendations for consideration by commissioners

- There appears to be significant challenges in accessing Speech and Language Therapy (SALT) in Nottingham despite high numbers of autistic children who are particularly likely to need SALT. Benchmarking of SALT provision against national guidance, exploration of the current provision and a health equity audit could inform future commissioning decisions.

- Feedback from parents suggests that there is insufficient information regarding SEND provision. Further work with the Communications team, informed by feedback from parents, will give children, young people and their families greater control through the provision of comprehensive and accessible information about the range of educational placements and support available, curriculum choices and alternative pathways.

- Continue to develop and improve the Local Offer, working with children, young people and their families to ensure the information is comprehensive and accessible.

- Provide support to children and families in the home and early years settings to promote early intervention and improved outcomes through well co ordinated early support services, so that parents have increased understanding and raised aspirations for their children and that admission to school is supported by personalised transition processes, resulting in effective inclusion of pupils in chosen educational placement.

- Predicted increases in the number of children and young people with SEND should be incorporated into forward planning of children's services. Modelling of these increases will more accurately inform service planning. For example services for extremely premature babies and those surviving longer with more complex needs.

- Some children and young people with SEND will be more vulnerable to infections and thus have an increased need for vaccination. All those working with this group could use a 'make every contact count' approach to encourage vaccination, specifically, to correct purveying myths around the safety of vaccinations such as MMR.

- Local intelligence suggests that children and young people with SEND sometimes miss out on health promotion interventions such as school-based sessions on sex and relationships and/or smoking, drugs and alcohol even though these sessions could be adapted to meet their needs. A review of this

provision could ensure that children and young people with SEND have equity of access to sessions that enable them to make informed decisions.

- Education support services will continue to work in partnership with schools to ensure they understand the requirements of the SEND Code of Practice, and have the knowledge and understanding needed to support the effective implementation of the legislative requirements. Further development of the links between special provision and mainstream schools will extend the good practice, knowledge and expertise available across all settings, as part of on going CPD opportunities for teachers and support staff.
- Raise educational achievement of children and young people with SEND through early identification of need, appropriate intervention and effective monitoring of progress towards challenging targets.
- Continue with Nottingham city's plan to convert statements to EHCP by 2018. The City is on target to convert all statements to EHCP's by August 2017. This activity will ensure that all young people and families will have access to the benefits of the EHCP including personal budgets where relevant.
- Review the role of the key worker service in supporting the implementation of EHCPs. This review will ensure that the best aspects of the service are retained and that the service is sustainable in the longer term.
- The range of short breaks available to disabled children and young people is limited and is not always sufficiently tailored to meet individual needs. A broad range of short breaks should be developed to include those delivered through internal provision, commissioned services and purchased through personal budgets.
- Conduct a review of the contract carers scheme to ensure family based overnight short breaks can be provided for children and young people with a range of disabilities.
- Literature suggests that there is an under representation of some ethnic minorities in diagnosis of SEND e.g. autism. It is unclear whether this is this due to lack of awareness within these communities, stigma around disability or professionals not diagnosing in these groups. Further exploration of this under-diagnosis is warranted.
- Nottingham's population is diverse; services may need to be adapted to meet the cultural needs of different communities to ensure equity of access and outcome.
- Consanguinity is a significant risk-factor for some disability. It is unclear whether more action could be taken to highlight the risk to relevant communities and to mitigate risk, through genetic screening, where there are known risks.
- Work in partnership with communities to take an asset based approach to children and young people with SEND focusing on what they can do, what family and friends can do, and only then what services are needed, to help people to live their lives.

- Ensure disabled children and adults aren't isolated from mainstream society through a comprehensive local offer which enables children and young people to access a range of mainstream/targeted/specialist activities where they are able to meet socially with their peers in an inclusive environment.
- Children, young people and families report that their experience of transition between services can be unnecessarily challenging. By conducting joint assessments parents/carers won't have to repeat their story to multiple professionals. In addition pooled, personal budgets (social care and health) could minimise duplication of assessment and payment processes.
- Ensure that disabled children's transition into adulthood is properly supported. Specifically, transition should be improved for children and young people with SEND who do not have an EHCP/statement and/or do meet the threshold for adult social care support.
- Many young people with SEND feel ill-prepared for adult life and unable to achieve their ambitions. Early years settings, schools and colleges should enable children and young people to have the information and skills they need to gain independence, transition to adulthood and achieve their ambitions including gaining meaningful employment.
- The tracking of the destinations young people with SEND after their 19th birthday should be improved to increase understanding of what pathways are working, which need developing and which should be decommissioned.
- Whilst considerable action has been taken people with learning disability are still in healthcare institutions as adults. Further action needs to be taken to enable disabled people to live at home, near home or in independent living of their choice.
- Joint commissioning and/or pooled budgets have the ability to minimise duplication of effort and release cost savings that can be invested elsewhere. Nottingham City Council and Nottingham City CCG could explore joint commissioning opportunities for children and young people with SEND.
- Commission appropriate Information and Advice Services provision to meet the needs of children, young people and families within the Codes of Practice including through the development of a robust specification that meets the needs of all service users and the extended requirements of the Act in the longer term.

Full JSNA report

What do we know?

1) Who is at risk and why?

Children and young people with special educational needs and disabilities (SEND) are a broad and diverse group and include individuals with complex needs requiring multi-level support as well as those who require substantially less input (ChiMat 2016).

Special educational needs (SEN) is a legal definition:

> "*Children who have learning difficulties or disabilities that make it significantly harder for them to learn or access education than most other children of their age*" (Department for Education 2014).

SEN covers a wide range of need including behavioural, emotional and social difficulties, autistic spectrum conditions and specific learning difficulties such as dyslexia.

A person is disabled if he or she has a "…*physical or mental impairment that has a 'substantial' and long-term' negative effect on his or her ability to do normal daily activities*" (Equality Act 2010).

Children and young people who have special educational needs (SEN) experience significant barriers to learning but do not necessarily have a disability. Equally, children and young people with disabling conditions *do not* necessarily have SEN, but there is a significant overlap between disabled children and young people and those with SEN. The overall prevalence of disability is lower than that of SEN (Parsons and Platt 2013). Porter et al (2008) estimates that approximately three-quarters of 'disabled' children are also identified as SEN.

The risk factors for special educational needs and disabilities in children and young people arise from a complex interplay of health, social, economic, environmental and educational factors. In addition, gender and ethnicity appear related to the prevalence of special educational needs and disabilities but the mechanism underpinning these links are not always well understood.

The prevalence of all-cause childhood disability is higher among boys than girls in the early years, although by late teens the prevalence rate among girls is similar to that of boys (Gould and Ashton Smith 2011). Boys are nearly twice as likely to have SEN support or EHC

plan as girls. Gender has perhaps the strongest single association with autistic spectrum disorders (ASD), with the odds of identification for boys over six times the odds for girls. Evidence suggests that his may relate to under-diagnosis in girls rather than a high prevalence in boys (Kirkovski et al, 2013).

Teenage pregnancies increase the risk of adverse birth outcomes that is independent of the important known confounders of low socioeconomic status, inadequate prenatal care and inadequate weight gain during pregnancy (Chen et al 2007). Increasing maternal age is a risk factor for Downs syndrome. The risk and severity of congenital malformations also increases with maternal age.

A number of risks are associated with drinking alcohol during pregnancy including Foetal Alcohol Syndrome and Foetal Alcohol Spectrum Disorders. Children born with Foetal Alcohol Syndrome (FAS) have restricted growth, a distinct pattern of facial features and physical characteristics and central nervous system dysfunction. Children with Foetal Alcohol Spectrum Disorders (FASD) do not show the full characteristics of FAS which means FASD is less likely to be correctly diagnosed. FASD develops in babies born to mothers with lower levels of alcohol consumption in pregnancy. Mother's drugs intake during pregnancy is positively associated with congenital malformation (Francine et al 2014).

Smoking is associated with low birth weight, prematurity and neurodevelopmental disabilities (CMO report 2012). Low birth weight, influenced by both genetic and social factors, is associated with a number of impairments/conditions, including cerebral palsy, reduced cognitive function and epilepsy (Moore et al 2012). For more information see the pregnancy JSNA chapter http://jsna.nottinghamcity.gov.uk/insight/Strategic-Framework/Nottingham-JSNA/Adults/Pregnancy.aspx

Viral infections in pregnancy such as rubella, herpes and cytomegalovirus can result in babies born with disabilities including sight and hearing loss, motor difficulties and learning disabilities.

Poor maternal nutrition can lead to adverse outcomes. There is strong evidence that consuming higher folic acid intakes before pregnancy and in the first 12 weeks of pregnancy will reduce the risk of neural tube defects such as spina bifida. Maternal obesity is associated with congenital anomalies and stillbirths. In addition, maternal obesity is linked to low breastfeeding rates.

The relationship between ethnicity and disability is complex. There is limited evidence to suggest that there may be an association between some impairments/conditions and ethnicity. For all-cause disability, there is an increased risk among children of mixed ethnicity and African/Caribbean origin (Blackburn et al 2013). For intellectual and developmental disabilities, rates of identification have been found to be lower among minority ethnic groups overall with the exception of higher rates of less severe forms of intellectual disability among Gypsy/Romany/Irish Traveller children and more severe forms of intellectual disability among children of Pakistani and Bangladeshi heritage (Emerson 2010).

In children and young people whose main reason for SEN support is speech, language and communication needs (SLCN) there is substantial overrepresentation of Black, Bangladeshi and Chinese pupils. For ASD there is substantial underrepresentation of Indian, Pakistani and Bangladeshi pupils but overrepresentation of Black Caribbean pupils. These disproportionalities reduce for SLCN when factors including social disadvantage are taken into account but the level of overrepresentation for ASD increases for Black African and Black Caribbean pupils and the level of underrepresentation remains high for Indian pupils (DfE 2011). Lindsay et al's study (2006) suggests that poverty and gender (male) have stronger associations than ethnicity with overall prevalence of special educational needs.

Consanguinity is a major risk factor for congenital anomaly because of the expression of autosomal recessive gene mutations inherited from a common ancestor. Couples who are first cousins are estimated to have about a 1.7% to 2.8% increased risk for significant congenital defects above the population background risk. The risk remains even after adjustment for deprivation, and accounts for almost a third of anomalies in babies of Pakistani origin (Sheridan 2013). In addition, health inequalities, including deprivation and access to healthcare, appear to have a role in the elevated risk of congenital anomalies within people of Pakistani origin (Ibid).

In terms of special educational needs, low-level parental qualifications, income poverty and being part of a non-working household all increased the 'odds' of a child being identified with SEN (Parsons and Platt 2013). The prevalence of 'mild disabilities' is higher in children from semi-skilled, manual and unskilled manual family backgrounds compared to children from professional family backgrounds. The rate of severe disability was highest amongst children from semi-skilled manual family backgrounds and lowest in children from professional and managerial family backgrounds. Holloman et al (1998) found that low maternal education was the most commonly associated factor with special educational needs.

Of all the childhood disabilities, neurodevelopmental conditions including autism, ADHD, developmental disorders and cerebral palsy, are the most common. Many of these children and young people experience a number of impairments and co-morbidities which, in conjunction with restrictions and barriers to participation, result in complex medical, educational and social support needs.

Disabled children and young people can lead full and fulfilling lives but for many, disability is associated with limited development and social participation, poor educational, health and employment outcomes (CMO report 2012). Children and young people with SEND do less well than their peers at all stages of education and are more likely to be out of education, training and employment at 18.

There is a strong association between childhood disability and family socio-economic disadvantage which is particularly marked for children who are 'statemented' (Parsons and Platt 2013). Disabled children and those with SEND are much more likely to live in poverty and experience social disadvantage than other children (Blackburn et al 2010). In 2015 28.7 % of pupils who were eligible for free school meals were also identified as having SEND (DfE 2015).

Children and young people with learning disabilities often have poorer health than their non-disabled peers. These differences in health status are, to an extent, avoidable and could be mitigated by the right support early in life.

Whilst the SEND code of practice states that '…*special educational provision is underpinned by high quality teaching and is compromised by anything less'* Ofsted (2014) stated that children with SEND who live in poverty were more likely to attend poorer quality schools (as measured by inspection ratings) in disadvantaged areas.

Children and young people with learning difficulties experience significant health inequities. A recent evidence review suggests that, when compared with their non-disabled peers, children with learning disabilities are more likely to:

- Live in an over-crowded, cold house and/or a house in a poor state of repair.
- Be exposed to inconsistent and harsh parenting and more chaotic family environments.
- At increased risk of exposure to violence, including bullying, physical, sexual, emotional abuse or neglect.
- Be exposed to a greater number and wider range of potentially adverse life events.

The Royal College of Paediatrics and Child health (2015) suggest that approximately 70% of looked after children have some form of SEND including ASD, ADHD and speech and language problems. In addition, mental health problems, such as anxiety and depression, are more common in looked after children**.**

Young people with learning disabilities are over-represented in the youth justice system. One in five young people in custody has a learning difficulty many also have mental health problems.

Transition is defined as a purposeful and planned process of supporting young people to move from children's to adults' services including health, education or social care services. Many young people with on-going needs fall through the transition gap or disengage with services at this point. Their outcomes remain unknown and are a serious cause for concern (NICE 2016). Poorly planned transition is not just extremely distressing for young people and their families, who already have a lot to deal with; it can also lead young people not to adhere to their treatment, resulting in greater illness, adverse social and educational outcomes, additional health service costs and even earlier death.

2) Size of the issue locally

2.1 Nottingham City population age 0-24 years

According to the Office of National Statistics 2014 Mid-Year Estimate (MYE) there are 314,300 people resident in Nottingham City. The population has been increasing at the rate of around 1% per year since 2011.

Nottingham has a young population, with 41% aged under 25 years (128,060 children and young people between the age of 0-24 years) compared to 30% nationally and regionally. The difference is accounted for by the student population as Nottingham population under 15 years (17.5%) is similar to national and regional averages. The Office of National Statistics (ONS) estimate Nottingham's population will increase by 10% by 2020; the school roll seems to be following this pattern. The school roll figures are higher than the ONS projection as the school roll contains children residing outside the city and may include children under 5 years old and over 16 years. For further details see the JSNA chapter on Demography 2015.

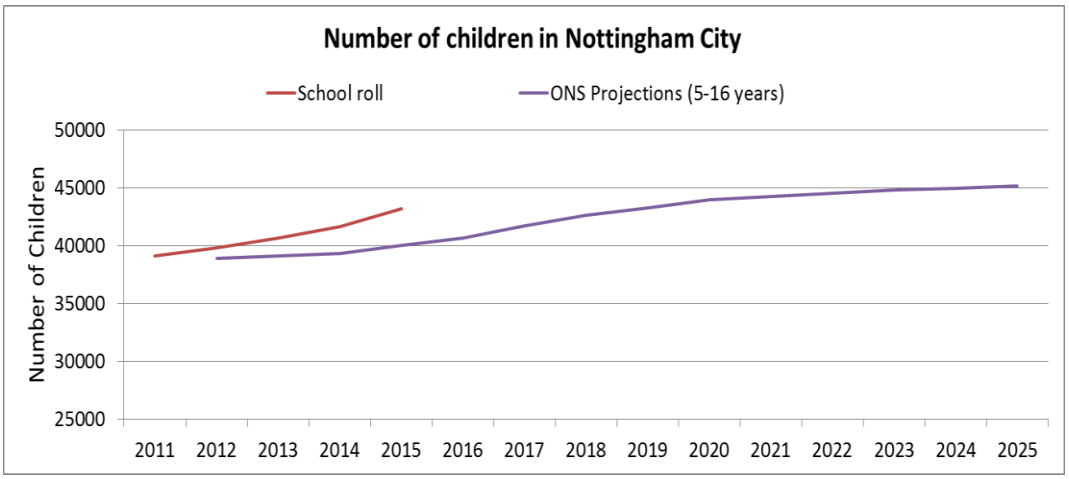


Figure 2.1 Population trend of school age children. Source: ONS

According to the Schools Census Data (2015) there are currently 45,695 children in Nottingham City schools (including Academies).This represents an increase of 7.6% since 2011[1].

2.2 Prevalence of Special Educational Need and Disability in children and young people

The number of disabled children (0-18 years) in England is estimated to be between 288,000 and 513,000 (Thomas Coram Research Unit, 2008). CMO estimate that 0.8 million disabled children and young people, aged 0 - 18 (6%) live in the UK. The mean percentage of disabled children in English local authorities has likewise been estimated to be between 3.0% and 5.4%. If applied to the population of Nottingham this would equate to between 1,978 and 3,560 children experiencing some form of disability (ONS mid-year estimates 2015). There is a degree of overlap between children with special educational needs and those with a disability (Parsons and Platt, 2013). Overall, the prevalence of disability is lower than the prevalence of SEN as not all children with disabilities will have special educational needs.

Local estimates of the numbers of children with SEN and disability have been based on various routine data sources such as the Statistical First Returns to the Department for Education, Disability Living Allowance statistics and local figures of numbers accessing children's services.

[1] Data derived School Census Summer 2011 – 2015. Provided by Information Management, City of Nottingham, Early Intervention.

2.2.1 Prevalence based on Disability Living Allowance

The number of children and young people in receipt of Disability Living Allowance (DLA) can provide an estimate of the number of disabled children and young people in Nottingham City.

There were 2,420 children under 16 years claiming DLA in November, 2015. Of these, 330 were under 5 years old. An additional 790 were aged 16-24 years, a decrease from 1,330 in 2014. These figures may be an under-estimate as there are an increasing number of children on a new payment system, Personal Independence Plan (PIP). PIP was introduced in 2013 and is gradually being rolled out across the UK. From October 2015, most DLA working age recipients (16 years and over) will have started to be invited to claim PIP. In April 2016, there were 873 PIP claims in payment which suggest that a large proportion are now receiving PIP instead of DLA. Based on DLA figures, the prevalence of disability for Nottingham would be 2.5% under 25 years and 4.1% under 16 years.

Table 3 shows the most common conditions for persons for which DLA was claimed for young people under 25 years in Nottingham. Over half the children and young people had conditions that indicate additional special educational needs.

Condition	Aged under 16	Aged 16-24	Age 0-24	Percentage 0-24 years
Learning Difficulties	1030	410	1440	45%
Hyperkinetic Syndromes	290	70	360	11%
Behavioural Disorder	310	20	330	10%
Neurological Diseases	140	70	210	7%
Unknown / Transfer from Attendance Allowance	120	10	130	4%
Disease of the Muscles, Bones or Joints	70	30	100	3%
Deafness	70	20	90	3%
Epilepsy	60	20	80	2%
Diabetes Mellitus	60	10	70	2%
Blindness	40	20	60	2%
Other condition	180	80	260	8%

Total	2420	790	3210	100%

Table 2.1 Children and young people in receipt of DLA by primary condition
Source: NOMIS, November, 2015

Figure 2.2 shows the DLA claims by ward for children under 16 years. In terms of rate per 1000 children, Bilborough has the highest DLA claim rate (70 per 1000 children aged under 16 years). This is significantly higher than the City average (43.5 per 1000) and may be due to the fact that the area contains a high proportion of bungalows and housing suited for those with disabilities.

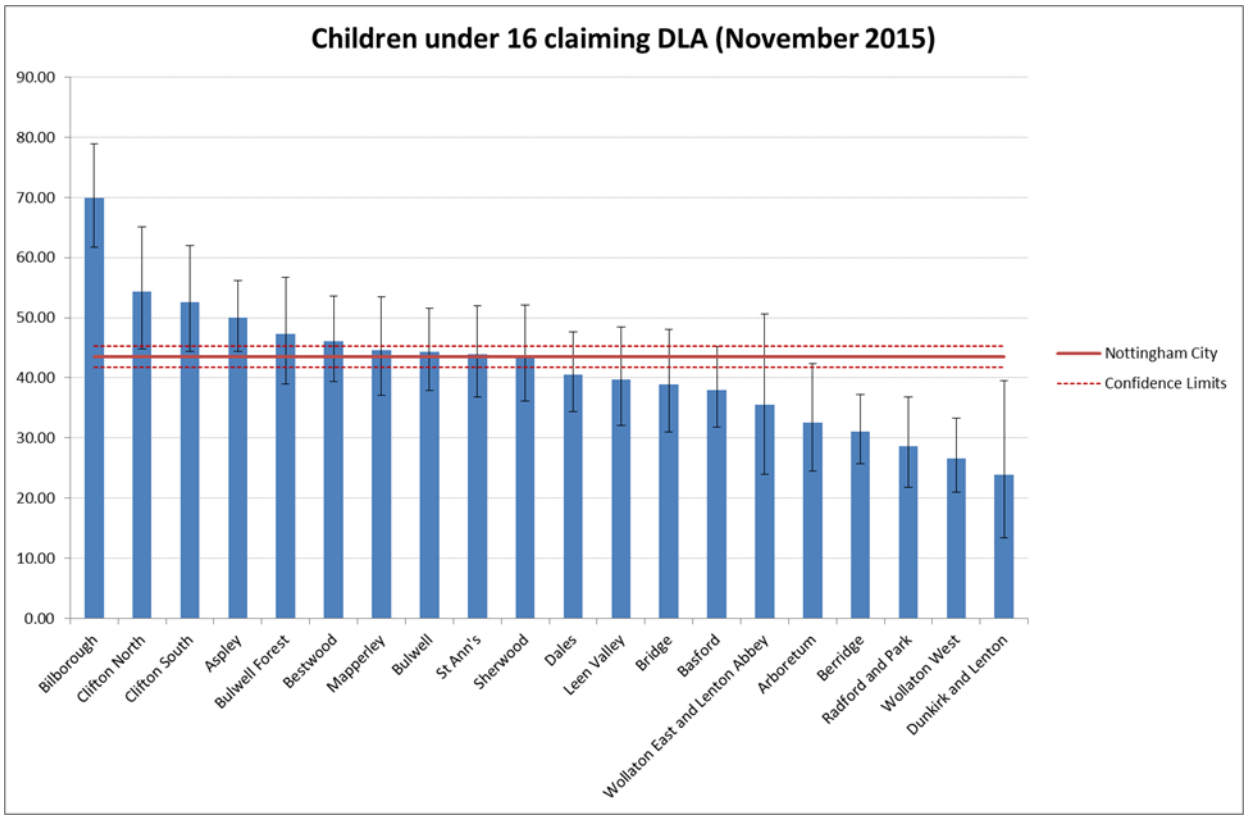


Figure 2.2 Children under 16 claiming DLA by ward November, 2015

2.2.2 Prevalence based on Special Educational Need in schools

Of the 45,695 children within Nottingham City schools in 2015, 7,387 (16%) have SEN. It should be noted that this includes children in City schools that are not resident in the city. Of those (92%) qualify for SEN support and 620 (8%) have an Education and Health Care Plan (EHCP) or statement of educational needs.

2.2.3 Numbers of children in contact with other services

It is estimated that 3,922 disabled children live in Nottingham City that meet the Equalities Act definition of disability. All of these children and young people are entitled to advice and support but not all will meet the threshold to access specialist services. Of these, approximately a 1000 children/young people have severe, complex and/or lifelong disabilities. This figure is based on a data collection from 2009 which hasn't been repeated. Local intelligence suggests this may be an underestimation of the actual number thus conclusions should be treated with caution.
Nottingham City Disabled Children's Register contains 1,025 children (Feb 2015). This voluntary register aims to capture information about all children and young people aged 0-25 years with disabilities or special educational needs in Nottingham City. The Disabled Children's Team provides support to 450 children.

In summary, data from a range of sources suggests that there are approximately 3,500-4,000 children in Nottingham with disabilities and 7,500 children with SEN of which a proportion also have a disability.

2.2.3 Ethnicity

The Thomas Coram Research Unit (2008) reports that, nationally, the percentages of disabled children by ethnic group are broadly similar to the percentages of children aged less than 17 years by ethnic group in the population. In Nottingham, over one third of the population under 25 years belong to a BME group with the next largest ethnic group, after White British, being Asian/Asian British (17%) followed by mixed/multiple ethnic group (10%).

The ethnic breakdown of the 1,025 children on Nottingham City Disabled Children Register in February 2015 was broadly similar to the census, with 38% belonging to a BME group.

2.2.4 Gender and the prevalence of SEND

Of the 6,659 SEN pupils in Nottingham City (October School Census, 2015, local data), 68% are male. This increases to 74% for children with statement or EHC plan. The mechanism underpinning in this is unclear but may relate to the number of conditions that appear more common in boys e.g. ADHD or chromosomal disorders such as Fragile X syndrome (National Fragile X Foundation 2015). In addition, evidence suggests that there is an under-

diagnosis of autistic spectrum disorder in girls rather than a high prevalence in boys (Kirkovski et al, 2013).

SEN Description	F	M	Total	% Male
No Special Educational Need	18850	17552	36402	48.2
SEN Support	1991	4038	6029	67.0
Statemented	97	291	388	75.0
Education, Health and Care Plan	65	177	242	73.1
Total	21003	22058	43061	51.2

Table 2.2: Number of children and SEN category by gender (October 2015)

This gender split in SEN roughly corresponds with national figures (SFR 2015). Boys are two and a half times more likely to have statements of SEN and three times more likely to have statements at secondary schools as compared to girls.

2.2.5 Poverty and socio-economic background

There is a direct link between SEND and poverty with SEND being a result, as well as a cause of poverty (Shaw et al). As table 2.3 shows the more deprived wards and neighbourhoods across the city tend to have higher levels of special educational need and disability incidence amongst pupils.

Ward	Children No.	Rate %	Rank by rate
Aspley	3205	50.3	1
St. Ann's	1540	45.8	2
Arboretum	790	43.9	3
Bulwell	1905	42.7	4
Bilborough	1780	40.5	5
Nottingham City	21605	34.4	

Table 2.3: Wards with the highest rates of children living in workless families or working families with an income below 60% of median income, August 2011
Source: HMRC Revised local child poverty measure, 2011

2.2.6 Looked after children

Looked after children are almost four times more likely to have special educational needs (SEN) than children who are not looked after and around ten times more likely to have a

statement of SEN (SFR41 2015). Nationally, 60% of looked after children have SEN[2] (SFR41, 2015).

Of 265 Looked After Children in Nottingham, 125 children (47%) had SEN and a 55 (21%) had statement of SEN[3]. This closely mirrors national figures. It is difficult to determine whether being looked after contributes to SEN or children are more likely to be looked after because of their SEN or other disabilities. Disruption to education through frequent moves and other emotional and behavioural difficulties are likely to be a factor.

2.2.7 Children in Care

Nottingham's Children in Care (CiC) cohort has higher numbers of children with special needs identified than nationally for children in care. Data gathered for the recent fostering inspection revealed 80% of Nottingham's CiC cohort had a special need identified. Nationally, there is a much lower prevalence rate of special needs within the child population of 25% (both CiC and none CiC (JSNA Children in Care, 2013).

2.3 Special Education Need Provision

In Nottingham, the majority of school pupils with SEN (without a statement) are educated within mainstream school. The majority of pupils with a statement of SEN or EHC (540 pupils, 76%) are educated within special school. The remaining 165 children with statements are educated within a mainstream setting.

An additional 435 children with SEND receive 'higher level needs' funding as their needs cannot be met without making additional funds available to the school they attend. In many Local Authorities, children need an EHCP to access this higher level of funding but in Nottingham a child does not need an EHCP to have this level of support. This means that children and young people with very significant difficulties can have their needs met without the delay of a statutory assessment.

2.3.1 Trends in SEN Provision

Due to changes in the provision of SEN in 2014, from School Action Plus and Statements to SEN support and Education and Health Care Plans (EHCP), trends should be treated with

[2] 60.5% of the children looked after for at least a year at 31/3/2015
[3] Nottingham Model for Prevention and Early Intervention; Continuous for 12 months in 2013

some caution. England and Nottingham show a similar pattern over time though Nottingham has a higher proportion of children without Statements or EHCP and a lower proportion with statements or EHCPs. Nationally, the percentage of pupils with SEN support has fallen from 18.3% in 2010 to 12.6% in 2015. The percentage of pupils with SEN support in Nottingham City has fallen more rapidly from 26.9% in 2010 to 14.8% in 2015. In January 2015, 15.4% of pupils in schools in England have SEN (both types) compared to 16.4% in Nottingham.

Local intelligence suggests that, historically, the level of identification of SEN (school action and school action plus and now SEN Support) in Nottingham City Schools has been significantly higher than national expectations. There was considerable variation from school to school in identification practice. Since 2011, the LA and schools have worked closely together to provide a framework to support more consistent identification of needs at SEN Support. As a result, the numbers of pupils identified have fallen consistently. At present the numbers of pupils across the LA is at or slightly below national expectation and statistical neighbours.

The LA continues to work with schools to address identification where data suggests that the numbers are higher or lower than may have been expected, to confirm and moderate decision making processes. As new processes become established it is anticipated that levels of SEND will remain slightly above national levels.

The percentage of pupils in schools in England that have statements of SEN or an EHC plan has remained constant at 2.8% since 2009. As figure 2.3 shows, in Nottingham, the proportion of children with statements or EHC plans is lower than the national average but has increased slightly from 1.4% in 2009 to 1.6% in 2015[4].

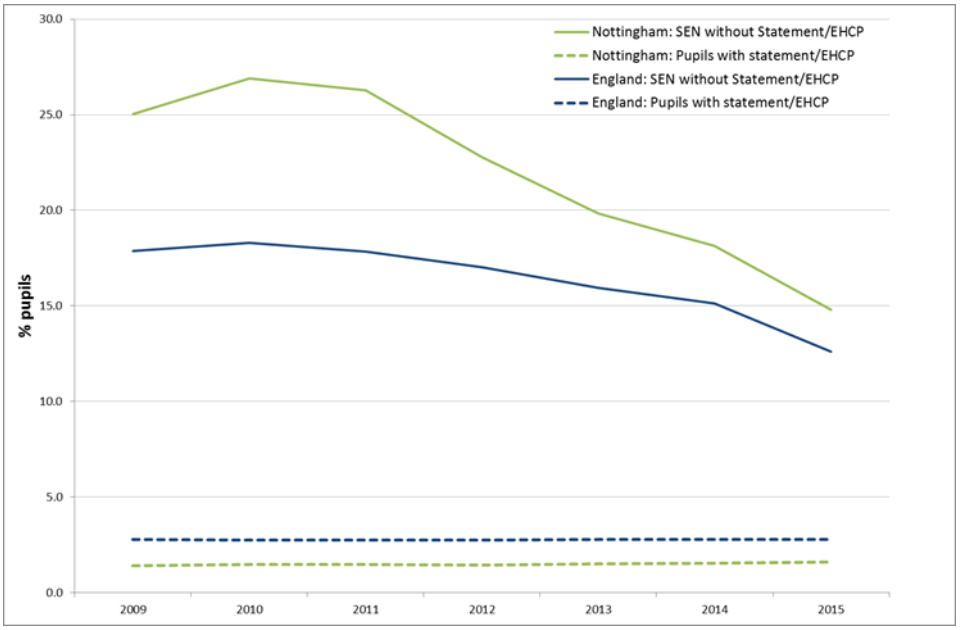


Figure 2.3 Percentage of pupils with SEN in all schools in England and Nottingham, 2009-2015. Source: SFR25 tables, Department for Education, 2015

The proportion of children in Nottingham schools with statements or EHC plans is nearly half that of England or Nottingham's statistical neighbours, though the trend is increasing compared to a small decrease nationally (figure 2.4). Nottingham City has one of the lowest proportions of Statemented/EHC children, ranking 147 out of 152 local authorities (2015). Nottinghamshire County is also lower than average at 1.3%. Nottingham City and County have had a long standing policy to avoid statementing which is time consuming and expensive, in favour of increasing the support in schools as a more effective use of scarce resources. Across local authorities, there is no relationship between the proportion of children with a statement and the proportion of children with statements achieving 5 A*-C grade GCSE's suggesting that lack of a statement does not impact on outcomes.

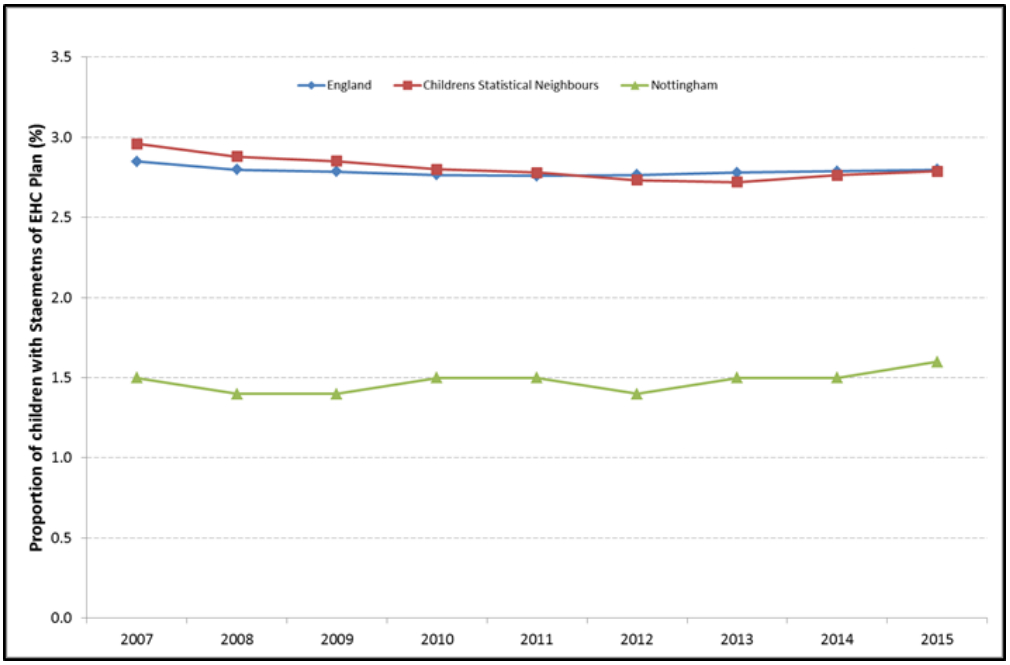


Figure 2.4 Proportion of children with Statements or EHC Plans in Nottingham compared with national and Nottingham Statistical Neighbours, 2007-2015
Source: SFR_25 Local Authority Tables, 2015, Department for Education.

Nationally, the continued decline in the number of children with SEN could be as the result of better identification of those children who have SEN and those who do not. This may have been as a consequence of the 2010 Ofsted Special Educational Needs and Disability review which found that a quarter of all children identified with SEN, and half of the children at School Action, did not have SEN (SFR SEN 2014).

In the 2015 Nottingham School Census (Summer), there were 644 children with either an EHC plan or statement (1.5% of the school roll compared to 1.4% Statemented the previous year). Across all categories of SEN, there were 7,167 children, 16.3% of the school role, compared to 20% in the previous year.

2.3.1 School type and provision

School type includes maintained and direct grant nursery schools, maintained primary and secondary schools, city technology colleges, primary and secondary academies including free schools, special schools, special academies including free schools, pupil referral units, alternative provision academies including free schools and independent schools.

Table 2.4 shows SEN distribution by school type in Nottingham City. The majority of children attend state funded schools. In the combined state nursery, primary and secondary schools

in Nottingham, 6,555 (15%) of children have SEN Support and 615 (0.4%) have an EHC Plan.

Within *Independent schools* there are 2,660 pupils of whom 175 (6.6%) have SEN. Of those identified as SEN, 170 have SEN support and a further 5 have EHC plans. The majority of pupils at Independent schools are not Nottingham residents. Within *Non maintained special schools* there are 90 pupils, 85 have a statement or EHCP.

School Type	Total Pupils	Without SEN	SEN support	Statement/ EHC plan
Independent school	2660	2485	170	5
Non-maintained special school	90	5	0	85
Pupil referral unit	170	30	140	0
State-funded nursery	125	110	15	0
State-funded primary	26915	22620	4220	75
State-funded secondary	15295	13045	2165	85
State-funded special school	470	0	15	455
Total	45720	38290	6725	705
State Schools	42975		6555	615

Table 2.4 SEN distribution by school type in Nottingham City
Source: SFR_2015 Underlying data, Department for Education, 2015

2.3.2 SEND by primary need

There are 13 categories for primary need in the SEND guidance although children may have more than one condition and a range of needs.

Moderate learning difficulty is the most common primary need for SEN support in state maintained primary and secondary schools in Nottingham (Figure 2.5).

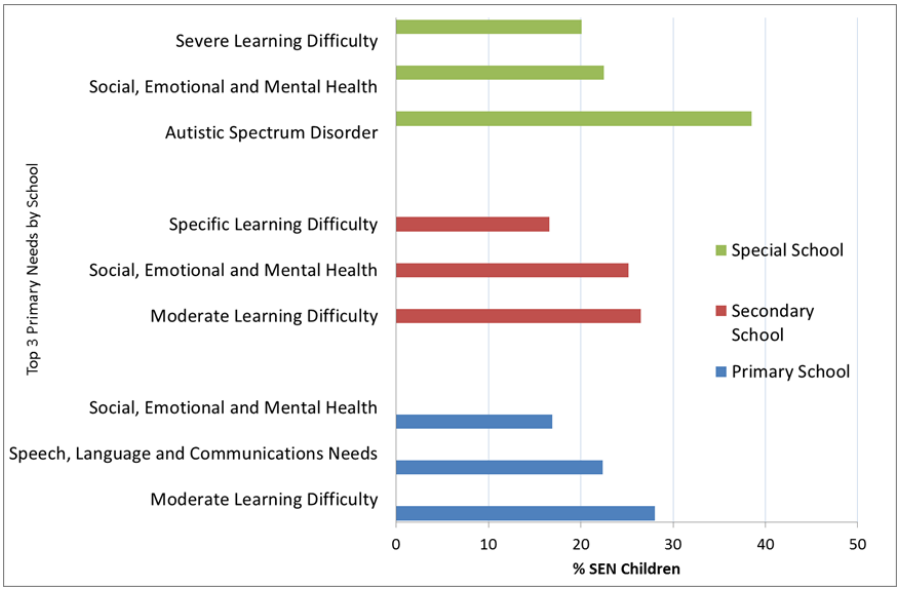


Figure 2.5 The top three primary SEN need by school type in Nottingham (2014)

Although speech, language and communication needs are the second most common primary need in primary school (22.4% of pupils with SEN), only 5% of secondary school pupils state this as their primary need compared to 9.8% in England. Despite this, local intelligence suggests families are having difficulty accessing speech and language therapy (SALT) services.

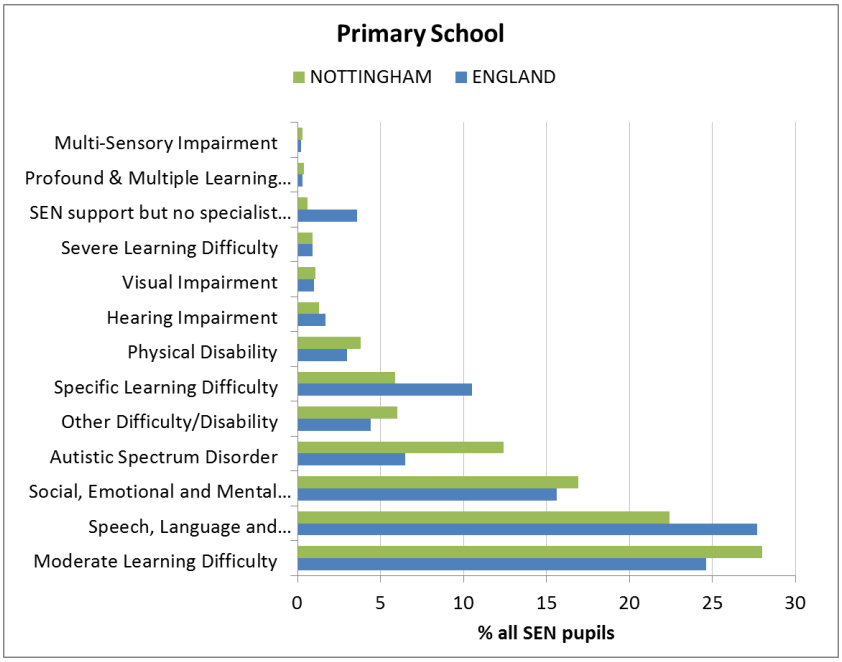


Figure 2.6 Proportion of pupils in primary schools with statements/ EHC plans and SEN support by primary type of need in England and Nottingham, January 2015
Source: SFR 25/2015: Special educational needs in England, January 2015

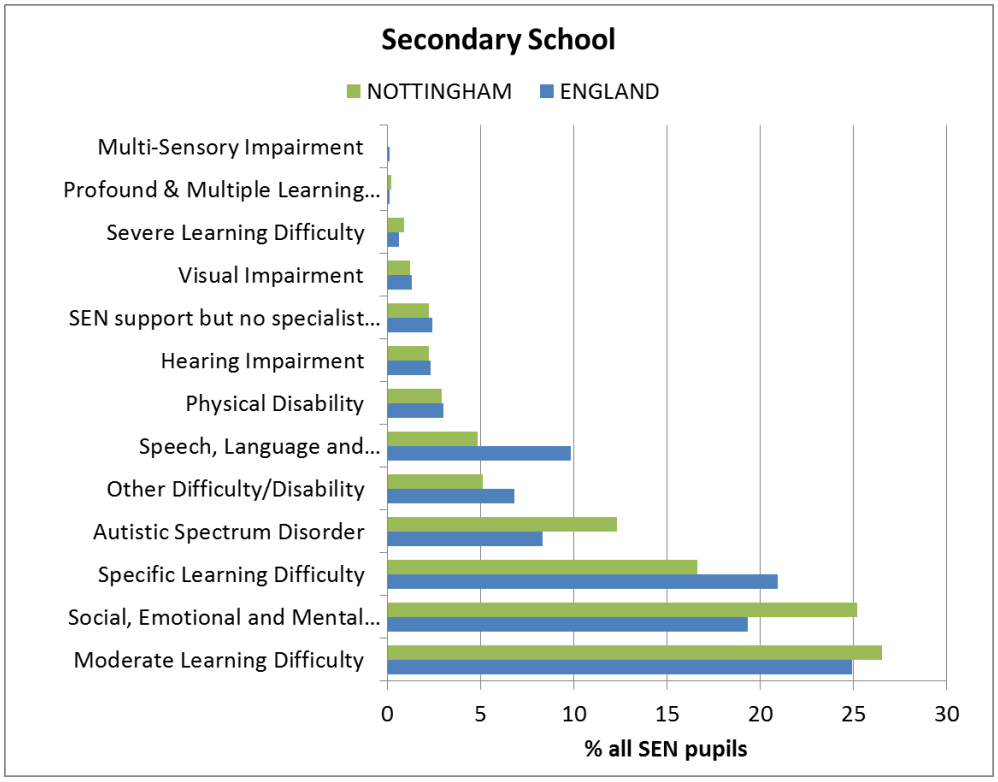


Figure 2.7 Proportion of pupils in secondary schools with statements/ EHC plans and SEN support by primary type of need in England and Nottingham, January 2015
Source: SFR 25/2015: Special educational needs in England, January 2015

As figures 2.8 and 2.9 illustrate the proportion of pupils identified with Autistic Spectrum Disorder (ASD) as their primary need is higher in both primary and secondary schools in Nottingham compared to the England average (figure 2.6 and 2.7). ASD is the most common primary need for pupils in Nottingham Special Schools. Children who have yet to receive a diagnosis of ASD will be identified as having speech, language and communication needs (SLCN).

It is unclear why there are more children diagnosed with ASD in Nottingham. Some sources suggest that this is due to 'good' diagnosis services whilst others suggest children with Attachment Disorder and Foetal Alcohol Spectrum Disorder (FASD) are misdiagnosed as ASD[5]. Children who have yet to receive a diagnosis of ASD will be identified as having speech, language and communication needs (SLCN). If children and young people with the primary need of SLCN and ASD are considered together the numbers are similar to the England average.

[5] The presenting issues of ASD, attachment disorder and FASD are very similar, particularly in early childhood, which can lead to misdiagnosis.

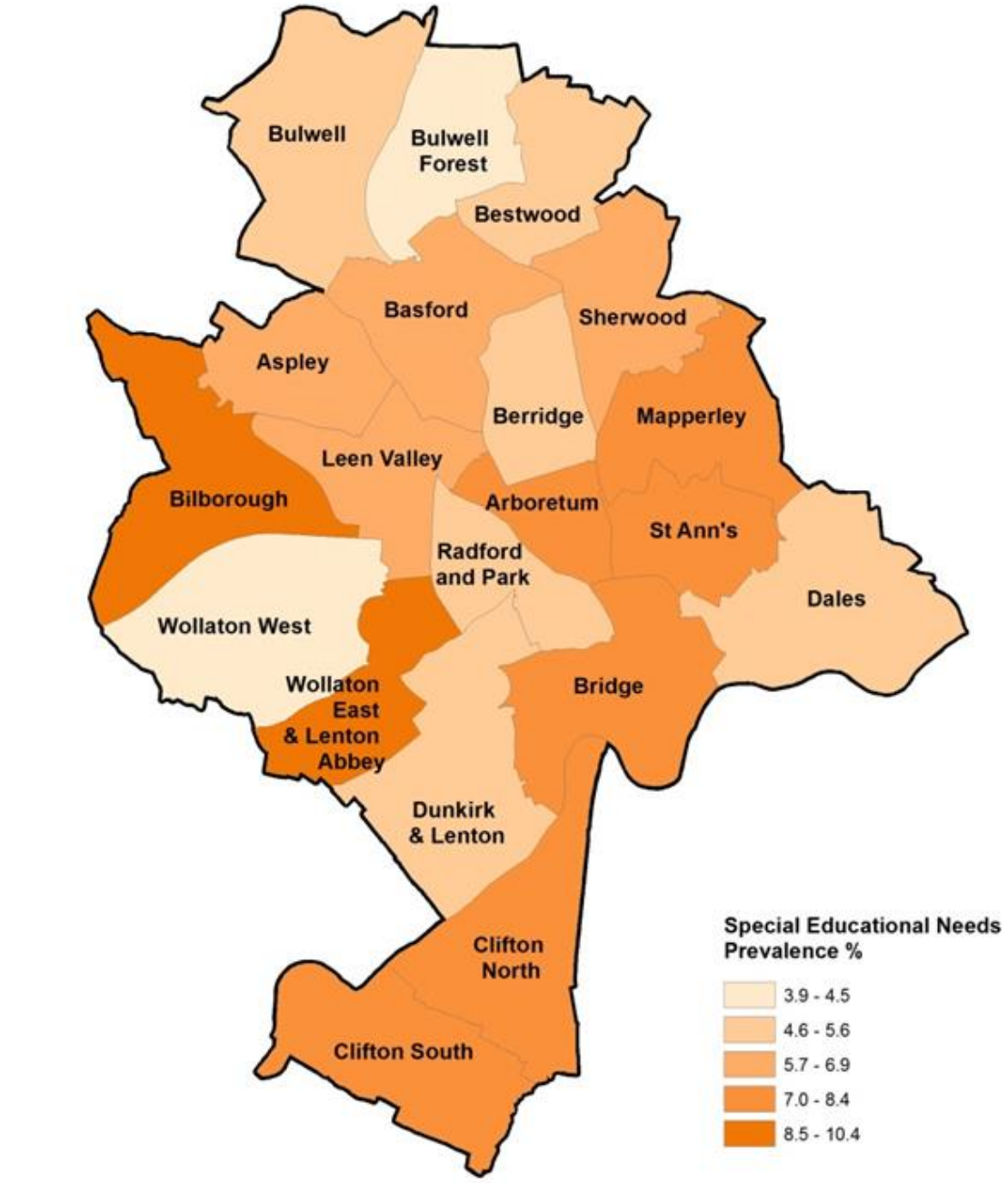
Many children and young people with ASD, including Asperger's Syndrome and Autism experience difficulties with speech, language and communication and imagination which can impact on how they relate to others. As Nottingham has higher than national levels of ASD there is likely to be additional pressures on SALT services.

2.3.3 Higher level SEN provision by ward

39,090 of the pupils on Nottingham city schools roll reside within the city, 2,668 are non-city residents. Aspley ward has the highest number of school pupils, followed by Bilborough and Bulwell.

Figure 2.8 and table 2.5 show the prevalence of children with School Action Plus and Statements by ward in 2014. Bilborough and Wollaton East & Lenton Abbey have the highest prevalence (% of children with SA+ or Statemented). However because of the small number of children in Wollaton East and Lenton Abbey, the high prevalence is due to a small number of children overall. The numbers of children with higher level SEN in Aspley and St Anns means that these wards, with Bilborough account for 30% of all children with higher level SEN in the City (table 2.5).

Figure 2.8: Prevalence of children on School Action Plus and Statemented by ward in Nottingham City (Jan 2014)



© Crown Copyright and database rights [2014]. Ordnance Survey [100019317].
You are not permitted to copy, sub-license, distribute or sell any of this data to third parties in any form.

Area	Ward Name	Pupils	With SA+ or Statement	Ward prevalence (%)	Proportion of City total with SEN (%)
E05001822	Arboretum	1304	102	7.8	4.0
E05001823	Aspley	4531	313	6.9	12.3
E05001824	Baseford	2499	158	6.3	6.2
E05001825	Berridge	2735	153	5.6	6.0
E05001826	Bestwood	2644	138	5.2	5.4
E05001827	Bilborough	2866	262	9.1	10.3
E05001828	Bridge	1402	103	7.3	4.0
E05001829	Bulwell	2766	156	5.6	6.1
E05001830	Bulwell Forest	1834	71	3.9	2.8
E05001831	Clifton North	1425	117	8.2	4.6
E05001832	Clifton South	1900	160	8.4	6.3
E05001833	Dales	2425	128	5.3	5.0
E05001834	Dunkirk and Lenton	400	22	5.5	0.9
E05001835	Leen Valley	1847	115	6.2	4.5
E05001836	Mapperley	1343	100	7.4	3.9
E05001837	Radford and Park	1308	71	5.4	2.8
E05001839	Sherwood	1403	89	6.3	3.5
E05001838	St. Ann's	2133	172	8.1	6.7
E05001840	Wollaton East and Lenton Abbey	326	34	10.4	1.3
E05001841	Wollaton West	1999	90	4.5	3.5
	Nottingham City	39090	2554	6.5	100.0
	Non City Residents	2668	215	8.1	

Table 2.5 Total number of pupils by ward, proportion on school action plus or statemented and percentage of city total (Jan 2014)

2.3.4 SEN provision by Ethnicity

Nationally, Black pupils are most likely to have SEN, both without statements (18.5%) and with statements (3.6%). Chinese pupils are the least likely to have SEN without statements (9.1%) or SEN with statements (2.2%; SFR25, 2015).

In Nottingham, the ethnic breakdown of children with SEN was broadly similar to the children without SEN, though children of Asian background were under represented in the SEN cohort compared to White children. In the school census for January 2015, 61% of children with SEN were classified as White compared to 55% of children without SEN. Within each ethnic group, the proportion of children with SEN ranged from 8% of Chinese children to

17% of White children. The proportion of children with statements or ECHP was similar in all ethnic groups in Nottingham.

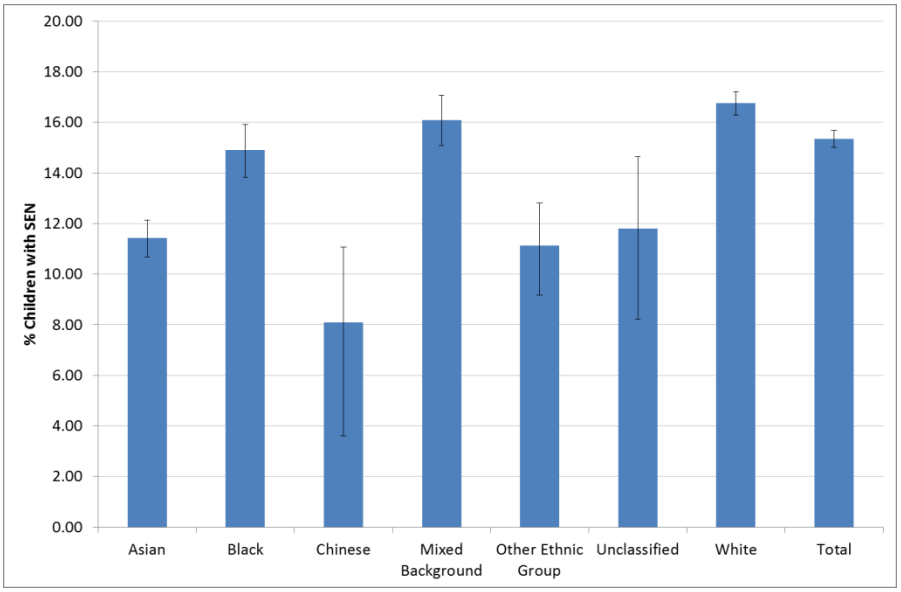


Figure 2.9 Proportion of children with SEN by ethnic group
Source: School Census, Nottingham City, January 2015

2.4 Educational Outcomes

Educational outcomes for children in Nottingham are poor compared to national figures, in part due to high levels of deprivation. For children with SEN, outcomes up to key stage 2 are broadly similar but once children with SEN reach key stage 4, outcomes are poorer in Nottingham.

Figure 2.10 show the progress of pupils with and without SEN at key stages 1, 2 and 4 and post-16. No data is available for key stage 3 as there is no national testing of this age-group.

Key Stage 1

Nationally, pupils with SEN perform significantly worse than pupils without SEN in 2014/15 and the attainment gap has widened in some subjects (mathematics and science). The gap is largest in writing (44 percentage points), and smallest in mathematics (31 percentage points). In Nottingham, attainment is generally 4 to 5 percentage points below the national average. There is a similar picture with the widest gap in writing and smallest in mathematics (no figures for SEN with statement due to small numbers involved).

Key Stage 2

Nationally, 40% of pupils with SEN achieved the expected level in reading, writing and mathematics in 2013/14 compared to 90% of those with no SEN, rising to 42% if Statemented children are excluded. In Nottingham, 88% children with no SEN achieved the expected level in reading, writing and mathematics compared to 50% of children with SEN (excluding Statemented children as figures not published).

Key Stage 4

Nationally, in 2013/14, 20.5% of pupils with SEN achieved 5+ GCSEs at A*- C or equivalent including English and Mathematics, 44.8 percentage points lower than those with no SEN (65.3%). In Nottingham, 23% of children with School Action provision achieved 5+ GCSEs at A*-C or equivalent including English and Mathematics compared to 28.7% nationally (Only school action figures are published at LA level). Note that due to reforms introduced in 2014 data is not comparable to earlier years.

Post-16 – attainment by age 19

Nationally, 77% pupils with no SEN achieved 5+ A*- C including English and mathematics by age 19 in 2013/14, compared to 72% in Nottingham. Only 34% of SEN pupils without a statement achieved 5+ A*- C GCSEs in England (2013/14) compared to 27% in Nottingham. Only 4% of young people in Nottingham with statement achieved the level, compared to 13% nationally.

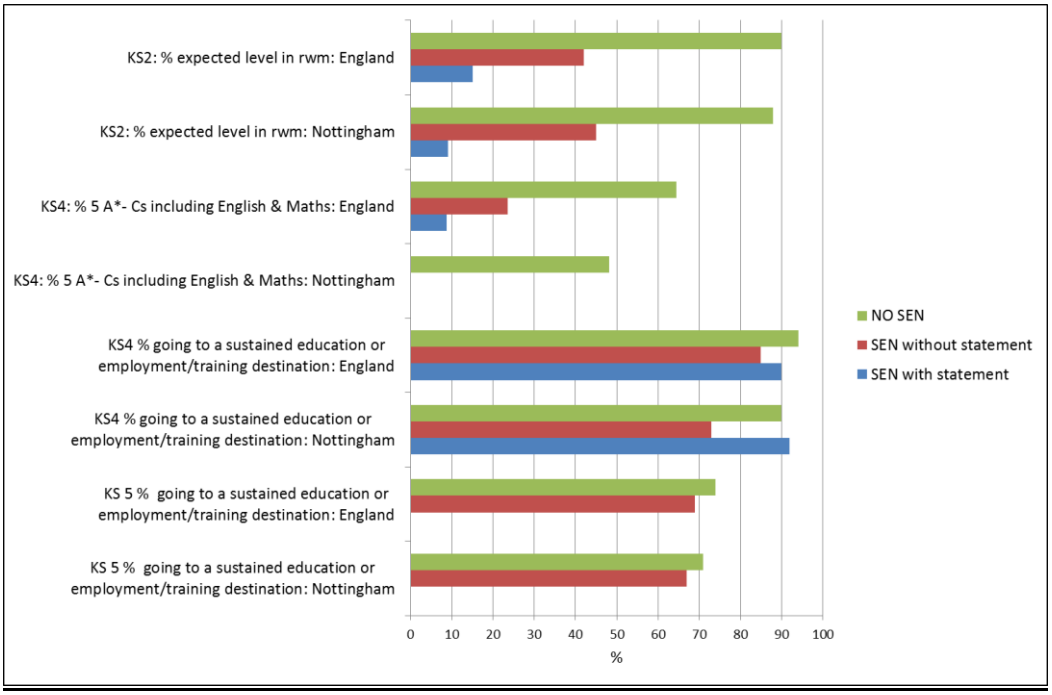


Figure 2.10: Outcomes for SEN children in England and Nottingham at Key stage 2 and 4 (2014). Source: LA SEN database January 2015 (Local Authority Data on Funding and Characteristics of High Needs Pupils) Nottingham data missing where numbers suppressed to reduce risk of disclosure.

2.4.1 Absence and Exclusion

Absence

Nationally:

- 7.5% of sessions were missed for pupils with statements in 2013/14
- 6.7% for pupils identified as School Action Plus
- 5.7% for pupils identified as School Action
- 4.1% for pupils without SEN.

Nationally, pupils with the primary SEN category profound and multiple learning difficulties were most likely to be absent from school in 2013/14, missing 13.7% of sessions. 11.0% of pupils with statements were persistent absentees, missing around 15% or more sessions, in 2013/14 compared to 2.6% of pupils without SEN.

In Nottingham, primary school children with SEN support missed 6% of sessions compared to 7% sessions missed by children with EHC plans or statements and 4% missed by children with no SEN. Secondary school children with SEN support missed 8% of sessions compared to 5% sessions missed by children with EHC plans or statements and 5% missed by children with no SEN. Children in special schools missed 10% of all sessions. Overall, children with statements or EHC plans missed 10% of possible sessions (Local communication, Nottingham City, Education, 2015).

Exclusions

5.2% of pupils with SEN without a statement received one or more fixed period exclusion in 2013/14 compared to 6.4% of pupils with statements and 1.1% of pupils with no SEN (DfE 2016). In Nottingham, 6.2% of pupils with SEN without a statement received one or more fixed period exclusion compared to 4.0% of pupils with statements and 1.9% of pupils with no SEN (DfE, 2015).

2.4.2 Not in Education or Training (NEET)

In March 2014, 91% of 16-17 year old Nottingham residents without Learning Disability were in education or training, similar to the national average. Of those with a learning disability, 82% were in education or training compared to 85.8% nationally.

It is estimated that 65% of people with learning disabilities would like a paid job[6]. However, in 2010/11, only 6.6% of adults with learning disabilities in Nottingham were reported to be in some form of paid employment; the majority of people with learning disabilities who are in employment, work part-time. Men were more likely to be working 30+ hours per week than women (1.3% v 0.4%). Employment rates varied considerably across Local Authorities, ranging from 0-36%[7].

2.4.3 Destinations

Pupils with SEN or LDD were less likely to progress to Higher Education than other pupils (SFR 2014). Nationally, In 2010/11, 59% of disabled graduates were in employment and 15% were assumed to be unemployed. This compares to 65% and 11% of non-disabled graduates. In the same period, 16% of disabled graduates were in further study compared to 15% of non-disabled graduates[8].

In Nottingham very few schools have a 6th form so the majority of children (80%) attend college compared to England where the proportion attending college is 52%. Nationally, 66% of SEN children and 69% of Non-SEN children continued in education or employment or training. This compares to 67% and 74% respectively in Nottingham state funded mainstream colleges (Students, in 2012/13, who entered an A Level or other Level 3 qualification, going to, or remaining in, an education or employment destination in 2013/14; SFR022016_KS5_LA_Destinations).

2.5 Summary Statement

- The size of the local population and the number of children on the school roll has increased since 2010.
- 80% of Nottingham's children in care cohort have SEN's.
- The majority of children with SEN are educated within mainstream school.

[6] Report - Valuing Employment Now
[7] Source: People with Learning Disabilities in England 2011
[8] Higher Education Statistics Agency (February 2013) Destinations of Leavers from Higher Education Survey (DLHE)

- The majority of children with a statement or EHCP are educated within a special school.
- There is a direct link between poverty and SEND within the city.
- The percentage of pupils with SEN in Nottingham City has fallen from 21% in 2013 to 16.4% in 2015 although; this is still above regional and national averages.
- The percentage of children with a statement/ EHCP in Nottingham, 2.8%, is considerably lower than the national average of 1.4%.
- Attainment is lower for CYP with SEND at all levels of education than their peers.
- CYP with SEND are more likely to be absent or excluded from school than their peers.
- The destinations of children and young people with SEN in Nottingham are lower than their peers in England

3) Targets and performance

1. **Targets and performance**

The Public Health Outcomes Framework identifies a range of outcome measures related to the school aged population. The majority of these are equally; if not more, relevant to children and young people with SEND. These include:

- Improving School readiness
- Reducing Pupil absence
- Reducing excess weight in 4-5 and 10-11 year olds
- Improving population vaccination coverage

PHOF 1.02 Improving school readiness

This indicator measures how prepared a child is to succeed in school cognitively, socially and emotionally. Children are assessed as whether they have, or don't have, a 'good level of development' (GLD) at 5 years. Having SEND can impact on children reaching a GLD. Children with a statement of education needs are 3.5x less likely to have a GLD compared to those who do not have one (Public Health England 2015)

These children may need additional support to fulfil their potential. For example, children with SEND may benefit from adapted learning strategies and environment, support around speech, language and communication difficulties and/or support to manage sensory, emotional or physical needs.

The PHOF also considers the percentage of children with free school meals achieving a good level of development at the end of reception. These are important figures to consider as it is known in the UK that pupils identified as having special educational needs are disproportionately from disadvantaged backgrounds.

PHOF 1.03 Pupil absence

Pupil absence is measured as the percentage of half days missed due to authorised or unauthorised leave. As pupils with SEND are much more likely to be absent or excluded from school, this outcome may be of particular importance (Ofsted 2010).

PHOF 2.06 Excess weight in 4-5 and 10-11 year olds

This is particularly relevant as children and young people with SEND are more likely to be classified as overweight or obese. The proportion of children who are classified as either overweight or obese is highest where the child has a limiting illness and a learning disability (ChiMat 2011).

PHOF 3.03 Improving population vaccination coverage

Uptake of vaccinations is a key indicator as to the level of protection a population has against vaccine preventable communicable diseases as coverage is closely linked to levels of disease. Many children and young people with disabilities will disproportionately benefit from vaccination due to associated physical disabilities which can make infections such as influenza more serious. The combined Mumps Measles and Rubella (MMR) vaccination is given as part of the routine vaccination schedule, usually within a month of their first birthday and as a booster dose before starting school. Despite having been conclusively disproven, the suggestion of a link between MMR and Autism and Crohn's disease still influences parent's decisions today (PHE 2014).

The NHS Outcomes Framework is a set of 68 indicators which measure performance in the health and care system. A number of areas where the outcome measures for children and young people could be improved have been highlighted by the Children and Young People's Health Outcomes Forum (Department of Health (DH) 2013). The 2015/16 update (DH 2014) of the NHS outcome framework highlights an intent to extend outcomes to consider pupil absence from school for people with long term conditions, disability and/or

mental health problems but that databases had yet to be fully developed. However, within the context of young people with special educational needs and disability, a number of existing outcomes hold particular importance both for young people and those who provide them with help and support on a day-to-day basis:

- **Reducing mortality in children:** This domain captures how successful the NHS is in reducing the number of avoidable deaths in children. Children and young people with disabilities are more likely to die in childhood including from modifiable causes.

- **Health related quality of life for carers:** this outcome measures the quality of life of carers who have long-term health conditions. Many carers, including those with caring responsibilities for children and young people with SEND, experience poorer health than those who are not carers as their caring responsibilities make it challenging to manage their own health.

- **Improving the quality of life for people with multiple long-term conditions:** This indicator is currently in development. It will look to capture how successfully the NHS supports people with long-term conditions to live as normal a life as possible.

- **Emergency admissions for children with lower respiratory tract (LRTI):** This indicator measures adverse outcomes for those with conditions, in this case LRTI, which should normally be managed in a primary or community care setting infections. Children and young people with disabilities are more likely to be admitted with LRTI than their non-disabled peers.

- **Children and young people's experiences of inpatient services:** This indicator is currently in development and will be based on paediatric inpatient surveys. It is part of a continued commitment to ensure people have a positive experience in care. Children and young people with disabilities are more likely to be admitted than their non-disabled peers.

Nottingham City Children and Young Peoples Plan (CYPP)

The Nottingham CYPP has a range of performance measures that relate to children and young people with SEND. These include:

- Number of referrals into the Behavioral, Emotional or Mental Health Pathway which lead to appropriate support from Child and Adolescent Mental Health Services (CAMHS).

- Gap between SEN and non-SEN pupils in achieving Key Stage 2 English and Maths threshold.

- Gap between SEN and non-SEN pupils in achieving 5 A*-C GCSEs including English and Maths.

- Children from disadvantaged groups achieve their potential.

Nottingham City Council Plan 2015-2019

- Create more special school places for children with additional needs
- Work with special schools to develop training and work placements
- Make Nottingham the fastest growing city for disability sports participation in England

Nottingham City CCG's strategy 'Working Together for a Healthier Nottingham: 2013-2016

Commissioning actions related to children and young adults with SEND include:

- Work with partners to develop accessible, family-focused and responsive services, including early intervention, which are tailored to the needs of children, their families and carers.

- Work in partnership with Nottingham City Council to promote access to education, training and development to ensure that all professionals involved in a family's care are skilled and equipped to deliver the latest evidence-based practice.

- Ensure access to parenting programmes that will enable parents and carers to understand the needs and behaviour of their children by sharing the information, advice and skills they need to provide good parenting.

- Promote the ‘Think Family’ approach, and implement the family support pathway to identify children and families most at risk of poor outcomes in health, education, and social care.

- Continue to develop effective child and adolescent mental health services in the community Improve the quality of care pathways to ensure that the transition from children’s to adult services is seamless and supportive Integrate services for children and young adults with acute and additional health needs (including disability and complex needs) to ensure a single point of access and co-ordinated assessment, treatment and review Implement personal health budgets for children and young adults with complex and continuing care needs.

- Develop and improve services for target groups, such as youth offenders, children in care, young carers and those with autism and ADHD.

The Nottingham Plan to 2020

The Nottingham plan aspires to halve the number of children living in poverty. Were this to be achieved it would disproportionately benefit SEND children and young people as they are more likely to live in poverty.

4) Current activity, service provision and assets

4.1 Prevention

Prevention of disability is achieved by reducing socio-economic disadvantage including reducing the risk of childhood diseases and exposure to environmental health hazards and increasing access to high quality health care. Across Nottingham colleagues work together to:

- Increase access to safe and healthy housing.
- Support parents to choose not to smoke reducing exposure to environmental tobacco in utero, infancy and childhood.
- Encourage mothers not to drink alcohol in pregnancy.
- Increase uptake of vaccinations against communicable diseases such as rubella which can cause damage to the foetus.

Nottingham University Hospitals (NUH) has Clinical Genetics service that supports individuals and families who are concerned about a suspected or confirmed diagnosis of a genetic condition. If problems are identified during a pregnancy, either because of screening tests or a family history, referral is made the Clinical Genetics Service who can provide information about genetic conditions and discuss options available to individuals and their families in a non-directive way.

4.2 Early identification of, and intervention in, special educational needs and disabilities (SEND)

Children may be identified as having SEND by their parents or carers, by nurseries and by schools or by health professionals. Early identification leads to better outcomes. Parents, children and young people should feel able to tell their school or college if they believe they have or may have SEN in order to access additional support. In addition, a child's parents, young people, schools and colleges have the right to request a needs assessment for an education and health care plan (EHCP).

4.3 Universal and community based support

General Practitioners may be the first professional parents/carers contact when concerned about their child's development. In addition, parents/carers may seek support regarding matters that could indicate special educational needs and/or disability such as problems with speech/communication, feeding/eating, sleep and behaviour. Thus the GP is well placed to identify potential SEND and refer to more specialist support.
If a child is diagnosed with special educational needs and/or disability the GP remains an important source of support.

Health Visitors have contact with every child at key developmental stages with this contact tailored to the needs of the individual child and family. Health visitors may identify developmental delay and refer to appropriate specialists. If special educational needs and/or disability are identified the health visitor can support the family including signposting to parenting courses for the parents of disabled children and/or autism.

School Nurses work with partners to provide support to school-aged pupils. Children and young people with SEND, and their families, can request support on a variety of issues including continence, weight management and concerns re emotional health.

Voluntary Sector Services (VCS) have a valuable role in supporting children and young people with SEND and their parents/carers. In Nottingham a range of play and youth sessions are delivered throughout Nottingham by the voluntary and community sector through the Area Based Grant funding programme. Organisations supported by volunteers and paid staff provide sessions delivering both universal and targeted activity to children and young people predominately aged 10 years and over. Although not specifically aimed at children and young people with SEND, organisations actively seek to ensure all can participate.

Nottingham City Sport & Leisure *have worked hard to increase access for children and young people with SEND and their families, improving the accessibility of all eight leisure centres. Recent achievements include the CredAble Access accreditation, awarded by national disability advice service Nimbus Disability, to buildings that meet its accessibility standards and make it easy for disabled customers to use its facilities. The programme of disability and inclusive sport and physical activities continues to grow with a range of over 30 activities each week hosted at facilities including the Disability sport hub venue Harvey Hadden Sports Village. There is a menu of dedicated disability sport or inclusive activities and events offering choice for young people, as well as new sensory room facilities at John Carroll Leisure Centre.*

The Local Offer website is a central point of information about services, support and activities for all children and young people with SEND from early years to transition to adulthood
http://search3.openobjects.com/kb5/nottingham/fsd/localoffer.page?familychannel=8

The **Ability Nottingham Inclusion Project** facilitates iinclusive opportunities for citizens with a disability and additional needs www.mynottingham.gov.uk/index.aspx?articleid=3197

Two information advice and support services are jointly commissioned with Nottinghamshire County Council, **Ask Iris**, a physical and online newspaper and **Ask Us** (formerly Parent Partnership) which provides a wide range of advice and guidance for parents or carers of children with SEND including representation at tribunals.

Futures support people to realise their career aspirations through the delivery of a range of products and services. Based in Nottingham they work with a wide range of partners,

employers, schools and colleges across the country www.futuresnn.co.uk
More information on Futures can be found in the 'transitions' section.

4.4 Specialist support

There are a number of services in place to support children with SEN and disabilities including provision based in social care, education and health services.

4.4.1 Children's Centres including the Early Help Team

Children's Centres including the Early Help Team are part of Children's Integrated Services Directorate and include Family Support workers and Play and Youth teams.

Work around the early intervention/SEND agenda includes:

- Seamless referral for those families who do not meet Disabled Children's Team threshold.
- Rolling out workforce development opportunities to increase confidence and competence of front line staff and, in turn, parents/carers.
- Reviewing and updating the core offer information on NCC website to further inform parents/carers of accessible open access sessions in their community for 0-25 year olds.
- Raising awareness of relevant partner teams including SENCOs, Sensory and Behaviour teams etc. of accessible Early Help Team sessions in the Community for 0-25 year olds.

4.4.2 Integrated and Social Care Services

Family support services form part of the Children's Integrated Services Directorate and consist of the following service areas:

- Children's Social Work
- Children in Care
- Safeguarding and Quality Assurance
- Children's Duty and Targeted services

Disabled Children's Team Social Work

The Disabled Children's team undertakes assessments of children with permanent and substantial disabilities who are in need of aids and adaptations, short breaks and support services, protection or whom are looked after. The service works with the personal budget team to provide services to meet the need based on a Resource Allocation System (RAS). The RAS identifies the range of services that a family can access. This is primarily delivered through internal provision but can be purchased through direct payments. Direct payments are principally used to employ personal assistants. The team also provides on going reviews and support for open cases. The team also have a key role in ensuring effective safeguarding mechanisms are in place.

Disabled Children's Team Occupational Therapy

The Disabled Children's Occupational Therapy Team work with children with disabilities, who meet the identified threshold, to support mobility within the home and support the process for major adaptations of the home and accommodation moves where adaptation is not possible.

4.4.3 Education

The Inclusion and Disability Service promotes the inclusion and attainment of children and young people with special educational needs and disabilities (SEND) by providing additional educational support in the school/early years setting. Support is currently provided by the:

Inclusive Education Service, which comprises the Autism Team, Learning Support Team and Sensory and Physical Team and Portage. The teams provide specialist support to children and families in the early years, schools and settings to promote effective early intervention and ensure appropriate provision is in place to ensure children and young people make progress and are prepared for transition to adulthood.

The Special Educational Needs (SEN) Team works closely with parents, schools, children and families' colleagues and health services to ensure that children and young people with SEN get the most out of their school life and maximise their achievements

The Behaviour Support Team (BST) supports mainstream schools to meet the needs of young people experiencing emotional, social or behavioural difficulties through a holistic and multi-agency approach.

The Community Educational Psychology Service provides expert knowledge in the social, emotional, behavioural, and cognitive development of children and young people. They work with are those 0-19 (shouldn't this be 0-25) with complex and multiple needs, those with autistic spectrum disorders, learning difficulties, attachment disorders, ADHD, anxiety disorders, selective autism, life threatening illnesses and those who have suffered stress and trauma.

Special Schools and focused provision. There are a number of Focus Provisions in Nottingham City. They have teachers with specialist knowledge in hearing impairment or autism.

Focus Provisions are centres within mainstream schools which:

- Provide for a very small number of pupils with particular types of SEND
- Have additional staff with specialist knowledge
- Have specialist equipment
- Take children with very significant needs which cannot easily be met at their local school

The aim is that children attending these schools will benefit from access to a mainstream setting as well as having a peer group of children with similar SEND.

Nottingham City Special Schools offer a full educational programme to children with a range of SEND. Staff working in special schools may also provide specialist advice to mainstream schools. Pupils at special schools may receive on-site input from health professionals such as physiotherapists and occupational therapists and may attend a mainstream school for some of their lessons. In order to be placed at a special school, a child must have an Education Health and Care Plan or a statement of SEN.

In special schools:

- All children have significant SEND
- All staff have specialist knowledge and expertise
- Classes are small
- Specialist equipment is available

There are currently five special schools in Nottingham City. Many of these schools teach pupils with a combination of different types of needs. Each one offers special teaching arrangements for particular types of needs.

In order to effectively meet the needs of children and young people with SEND the following actions have been taken:

- Expansion of Westbury[9] for children and young people aged 5-16 years with social, emotional and mental health needs, including high-functioning autism, whose behaviour means they can't access the curriculum in mainstream school.

- Specialist provision for children with autism at Bluecoat Primary.

4.4.4 Health services

The CCG is working closely with Nottingham City Council on implementing the Special Education Needs and Disability (SEND) reforms and responding to new legislation, Children and Families Act 2014 (CFA 2014) to move toward joint-commissioning services for children with disabilities and complex needs.

Integrated Community Children and Young People's Healthcare Service

The Integrated Community Children and Young People's Healthcare (ICCYPH) is delivered by County Health Partnerships and offers services to any child or young person aged 0-19 years with a clinical need for input from specialist community staff including speech and language therapists, occupational therapists, physiotherapists and/or community nurses. The provision follows the child wherever they may reasonably expected to be e.g. school, home, hospital, respite and leisure.

The service also includes:

- GP referral for community phlebotomy for the South and City CCGs
- Training including competency sign-off for parents, carers and 'circle of support'
- Key working service in partnership with *Family Action*
- Information and advice as part of the Nottingham and Nottinghamshire local authority offers.
- Embedded transitions support and planning across service with specialist transitions input available for more complex cases.

[9] Additional 42 places

In addition, a rapid response physiotherapy service is available for children and young people aged 0-18 years that have an underlying respiratory condition. The service aims to minimise acute hospital admission through active on-going management to prevent chest infection and optimize respiratory function in community settings and offer additional support in the acute setting.

Complex health school team

The service provides holistic care of children and young people with learning and/or physical disabilities who may have a continuing health care needs within Oakfield School in Nottingham City.

The children are assessed as eligible for this service through the Children's Continuing Care Process. The complex health nursing team and support children and their carers ensuring this is provided in partnership with them and, as far as possible, within the community they live. They work in partnership to:

- Reduce hospital admissions for children wherever possible.
- Promote and maximise children's physical and mental health and emotional wellbeing, signposting and making referrals.
- Ensure Safeguarding and Child Protection responsibilities are explicit throughout the service
- Identify early the children and families where additional preventive programmes will reduce their risks and improve future health and well-being, including safeguarding.
- Ensure that children and their families are involved in making decisions about their health care, both at the individual level and in relation to service planning and development.
- Children and young people with complex continuing care needs and disabilities requiring 1 to 1 support are able to access and maintain a school placement and thus access education.

Designated Key Working Service

The team provides a service to children and young people, predominantly with SEND, who have continuing care or additional health needs in line with the Children and Families Act (2014)[10]. The service:

[10] http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted

- Supports children and young people with SEND to receive the right care at the right time.
- Ensures that children and young people receive appropriate, high quality and value for money care in settings acceptable to them and delivers care and treatment outcomes as defined in their care plans.
- Involve children, young people and their parents/carers in decisions about their care.
- Improves partnership working and the provision of joined-up care including providing care closer to home.
- Supports early transition planning and pro-actively engages in the transition process
- Provide clinical and commissioning representation via a range of forums to ensure that the needs of children with acute, additional and complex health needs are represented.

In addition the service ensures that:

- All those with a combined health and social care budget have an independent support plan completed by a key worker.
- All those with a health only personal health budget will have a support plan completed by a key worker
- All those with a social care only personal budget have the choice of an internal support plan by a Disabled Children's Team Family Support Worker or an independent keyworker.
- All those with a combined education health and social care budget as part of an EHCP have an independent key worker.

Designated Clinical Officer (DCO)

Nottinghamshire CCGs have now jointly employed a Designated Clinical Officer to support the CCG in meeting their responsibilities as part of the SEND reform. The Designated Clinical Officer leads the support for CCGs to ensure they meet their statutory duties for children and young people with special educational needs and disability. The Special Educational Needs and Disability (SEND) reforms outlined in the Children and Families Act (2014) are focused on improving outcomes for children and young people with SEND and how education, health and social care work together to help children and young people aged 0-25 years to achieve their potential.

The DCO is commissioned jointly to cover Nottingham City and Nottinghamshire and is hosted by Nottingham North and East CCG. The rationale is that as specialist health services are commissioned from the same provider, the same processes need to be applied across CCGs and both local authorities to align processes.

In addition, on behalf of City and County CCGs the DCO works with a range of stakeholders, including children, young people and their families, on a range of key areas including:

- Education, Health and Care Plan Pathway(s)
- Personal Health Budgets
- Continuing Healthcare for children and young people
- Pooled budgets through section 75 agreements
- Supporting pupils with medical conditions in schools
- and Care Treatment Reviews (Transforming Care).

Children's Continuing Care Service

This team provides specialist assessment and offers a multi-agency package of care when needed to support the family caring for a child or young person with multiple, complex and enduring health care needs due to disability, accident, life limiting or sudden illness.
The CCG monitors that all children and young people who are referred for a continuing care assessment will have a decision for eligibility made within 6 weeks of referral.

All children assessed as eligible for continuing care are offered a personal health budget to give them greater control over their healthcare. Under the Children and Families Act (2014) parents have the right to request a personal budget, including for health service provision, for children with Special Education Needs and complex health needs. There is a focus on more personalised care provision that is flexible, responsive and incorporates the requirements of children and parents. Currently only 4 children in Nottingham City have chosen to have a personal health budget.

4.4.5 Behavioural, Emotional and Mental Health Services/CAMHS

Children and young people with SEND are more likely to develop mental health problems than their peers. The Behavioural, Emotional and Mental Health (BEMH) pathway supports professionals working with children or young adults, and their parents/carers, who have emotional health or wellbeing needs. The pathway can also be directly accessed by parents/carers and young adults. The pathway is for children and young adults registered

with a Nottingham City GP aged from 0-19 years or to 24 years for young adults with a special education need (SEN) or a learning disability (LD).

Specifically, the BEMH pathway is for children and young people who present with concerns about their behaviour, emotional wellbeing or mental health and/or concerns about possible ASD or ADHD. The pathway aims to:

- Identify at the earliest opportunity where emotional wellbeing support is needed
- Ensure that the right early intervention and support strategies are put in place,
- Guide referrals to existing services provided by partner organisations across Nottingham City, this may include referrals to more specialist services
- Join-up current services and support for emotional wellbeing into a seamless pathway
- Enable timely multi-disciplinary assessment by the most appropriate professional
- Ensure there is ongoing person-centered support planning and that multi-agency support is implemented

In addition to assessment the BEMH team provide parenting programmes including specialised programmes for the parents/carers of children with a diagnosis of autism or ADHD.

For more information go to; Pathway for Children and Young People with Behavioural, Emotional or Mental Health Needs

4.4.6 Transport provision

Local Authorities have a statutory duty to provide travel assistance free of charge for children and young people with special educational needs and/or disabilities (SEND) between home and school at the start and end of the school day. Nottingham city provides transport in a number of ways, this includes an internal fleet of vehicles, external contractors, mileage allowance for parents/carers and public transport travel pass. In addition it also runs a travel training scheme to enable young people to take the journey from home to school independently.

4.4.7 Short breaks

A variety of short breaks are offered to children and young people in Nottingham dependant on the needs of the child/young person. Short breaks are accessed via pathways that identify need. All Short Break services are subject to 6 monthly/annual outcome focused review. Further details on the pathways can be found in appendix 1.

Nottingham City Council currently commissions two short break's services, Fun days for the summer holidays and Autism East Midlands (Formally NORSACA) for after school and weekend provision. It is recognised that the services provided are not sufficient to meet current need and new services are being commissioned to extend the range offered. In addition a 'Quality Provider' list of short break services will be developed which families can purchase through the use of direct payments.

The **Link Work Service** provides community based 'short breaks' for disabled children aged 5-19 in the form of social education. This is provided generally by 1 to 1 support in order to access community based activities. This support, whilst providing both young people and parent/carers with a break, focuses on achieving positive outcomes and having fun. The service aims to develop friendships, social skills and confidence for our young people. It also gives young people the chance to try new and exciting things.

The **Short Breaks Sitting Service** provides home-based 'short breaks' for disabled children aged 5-19. These short breaks enable parent/carers and siblings time to spend together outside of the family home in the knowledge that the young person is supported by someone who they know and trust. A sitting service aims achieve outcomes within the home such as developing personal care skills and understanding healthy eating. This service enables families to pursue their own interests.

The **Homecare Service** provides support to parents and young people with personal and intimate care. Often this is at times when a young person may need a little more support for example when getting ready for school or when going to bed. The service is designed to elevate some of the caring responsibilities from parents whilst providing young people with dignified support from carers that they like to spend time with.

Overnight short breaks are provided to disabled children and young people through the Nottingham City Short breaks fostering service. Approved foster carers provide tailored support within their own home, or for children and young people who have specific mobility needs, within a specially adapted bungalow. Stays are usually for 1-3 concurrent nights per month, but may be longer. Some young people, dependent on their pathway, may have regular weekly support. Carers within the service work hard to develop positive working relationships with children and families, helping to identify outcomes to work on, and provide a bespoke service which focuses on developing life skills and widening leisure opportunities for children.

Direct Payments are a method of accessing a Personal Budget for a child with SEND. They can be used to employ a Personal Assistant who could undertake a number of roles from enabling access to the community and positive social activities to personal care within the home.

Direct Payments can also be used in other ways including as a contribution to the costs of a family holiday or to purchase services from a specialist agency or organisation, such as Autism East Midlands. Essentially, Direct Payments can be used in numerous ways as long as they help achieve the outcomes expected for the child/young person and their family. Direct Payments can also be used to access a Personal Health Budget (PHB) for children/young people who are eligible for continuing health care.

In 2015/16 208 children in Nottingham received a Direct Payment through social care, health or a combination of both.

Crocus Fields is an overnight short breaks service for children and young people between the ages of 8 and 19 with learning and/or physical disabilities some of whom may have additional health needs. The service aims, through the provision of regular breaks, to assist families to stay together whilst caring for their disabled child.

Other benefits to children and young people who attend Crocus Fields is the positive social environment which supports young people with disabilities to grow as individuals and accept other people's differing behaviours. Some parents suggest that when their son/daughter starts accessing Crocus Fields they see a marked improvement in behaviour and social skills in their child. For more information www.crocusfields.co.uk

In order to access the service a Social Worker within the disabled children's team conducts a full assessment to determine whether a child/young person meets the criteria and if so, how many nights a year is appropriate for the family's needs.

CDC (City Hospital): Short Breaks Service offers care to meet the needs of children and young people (aged 0 – 19 years) who have complex health and disability needs. Day care is available for children and young people who meet the access criteria, and may be linked to the times when they are receiving therapy or a sensory session.

Referral for day care can be via a health professional such as a paediatrician. Up to 10 children and young people can be accommodated overnight. Referral to the overnight service is via a social worker, and then a Panel meets to decide how much care a child is entitled to receive. Parents are invited to this meeting. In the Short Breaks Unit, a named nurse is assigned to each child. The nurse works closely with the family to ensure that the care provided will meet their child's needs and reflect that which the child receives at home.

A review of short breaks in 2015 found that 423 children and young people had accessed 'short breaks support' at an overall cost of £2.83m. Engagement with parents is currently being provided through Rainbows. This service will be extended to deliver engagement and participation for children and young people.

4.5 Transition

Transition is defined as a purposeful and planned process of supporting children and young people to move between settings and services at key life stages such as nursery to school and/or children's to adults' services. Many young people with SEND will have transitions that encompass health, education and/or social care services. Effective support for transition is an expectation for all settings

Nottingham City Transitions Service is a citywide service. The team consists of 3 full time social workers who complete adult social care assessments for young people with disabilities and care leavers. Transitions services are provided to eligible young people who have received services from Disabled Children Team and Leaving Care Team. The team

aims to provide a seamless transition from children services to their adult provision, working in conjunction with colleagues from health and education.

The Nottingham City Transitions Service is part of a broader multi-agency **Targeted Transitions Team** hosted by Futures. The service has a number of specialist roles including Futures Advisers who work with disabled young people with a Statement or EHC, aged 13-19 and resident in Nottingham City. Support can include:

- Identifying appropriate post-16 placements
- Support to apply for education or training and sometimes to attend the interviews
- Support to identify any barriers to progressing on in learning e.g. travel training
- Help to identify your learning support needs that post-school providers will need to know
- Help to look at employment and training options

The specialist disability advisers work in all City special schools and can offer support to those with a Statement or EHC in mainstream schools.

Arguably transition can be equally challenging for children and young people with SEND who haven't been eligible for Disabled Children's Team support and/or who don't have an EHCP or statement. Feedback from parents, carers and colleagues suggest further action needs to be taken to enable smooth transition from children's to adult services for all young people.

The **Integrated Community Children and Young People's Healthcare** (ICCYPH) service supports the transition of children and young people with significant disabilities and/or health needs such as cystic fibrosis, muscular dystrophy and spinal muscular atrophy. Nurses support condition and/or disability management though a life-long approach. A named 'transitions nurse' coordinates transition ensuring that transition is facilitated through an individualized pathway rather than a simple chronological (e.g. at age 18) handover of care. Specialist transitions support is available for more young people with more complex needs.

In addition, the rapid response physiotherapy service currently has a pilot transition team to support patients already on the caseload at 18 years ago up to 25 years age. No new cases are expected referrals of young people aged18 years and over as they will automatically receive adult services.

5) Evidence of what works

5.1 Primary prevention

The Chief Medical Officer's report identifies a primary preventative approach for disability, stating that primary prevention is '…*likely to be best achieved through public policies to reduce exposure to social and environmental hazards*.' She suggests that strategic interventions at a national and local level should include:

- Reducing socio-economic disadvantage as children growing up in poverty are at higher risk for malnutrition, childhood diseases, exposure to environmental health hazards and often receive inadequate health care. These factors increase the risk of intellectual disability.
- Improving material environments such a safe and healthy housing.
- Reducing exposure to environmental tobacco in utero, infancy and childhood.
- Reducing exposure to alcohol in utero
- Ensuring population coverage of vaccinations against communicable diseases such as rubella which can cause damage to the foetus.
- Ensuring adequate dietary intake of key nutrients in pregnancy such as folic acid
- Reducing exposure to environmental hazards including air pollutants such as lead

Screening tests in pregnancy enables the identification of health problems that could affect women and babies including infectious diseases, Down's syndrome and/or physical abnormalities. The tests support choices about care or treatment during pregnancy and after the baby is born. For more information see http://www.nhs.uk/conditions/pregnancy-and-baby/pages/screening-tests-abnormality-pregnant.aspx

Screening tests offered to the parents of newborn babies include a physical examination of eyes, heart and hips, hearing screening and blood spot screening. Early identification of health conditions such as phenylketonuria or permanent hearing loss enables interventions to reduce the effects of the condition.

Genetic counseling can support parents to make informed decisions regarding the risks of genetic disorders. Midwives help identify which parents may be at increased risk of having a baby with a genetic disorder. For example, if a previous birth to either parent resulted in a child with a genetic disorder, unexplained intellectual disability or a birth defect and/or if the partners are blood relatives (The Arc 2016).

Obesity and disability – In England, at the start of pregnancy, 15.6% of women in England are obese (NICE PH27 2010). Pregnant women who are obese are likely to spend longer in hospital than those who are a healthy weight because of morbidity during pregnancy and labour related to their weight. Reducing maternal obesity will reduce the risk of congenital anomalies and stillbirths.

Prematurity: Msall et al's (1992) study suggests that in the premature infant risk factors predicting disability and/or SEN include sepsis, low socioeconomic status and non-white race. They conclude that whilst biomedical factors appear to confer the greatest risk of major impairments; socio-demographic factors appear to have a significant impact on educational risk in extremely premature infants who do not die.

5.2 Early Intervention

Children may be identified as having special educational needs and or disabilities (SEND) by their parents or carers, by nurseries and by schools or by health professionals. Early identification of SEND leads to better outcomes as additional support and interventions can be put in place to enable children to fulfil their potential. A range of interventions including parenting programmes, physiotherapy and occupational therapy and support programmes such as Portage can support the child to develop and avoid more costly interventions in the future.

Social and emotional wellbeing in the early years is particularly important as it lays a strong foundation for learning at school facilitated by healthier relationships and improved mental and physical health (Early Intervention Foundation undated). Assessments conducted by Health Visitors and other professionals seek to identify early infants or children who may be withdrawn, unresponsive, show signs of behavioural problems, delayed speech or poor language and communication skills.

Assessment: The DfE National Core Offer (2007) states that disabled children and young people should receive child-centred, multi-agency, co-ordinated services from the point of referral through identification and assessment to delivery.

Information, both disability/condition specific and on local services enables parents/carers to better understand their child's needs and identify sources of local support. Information regarding diagnosis and support available should be tailored to the individual needs of children and their parents and be readily accessible in a range of formats.

5.3 Staying well and fulfilling potential

5.3.1 Environment

Reducing socio-economic disadvantage to improve maternal health and wellbeing, and in turn child well-being, across the life course improves outcomes for disabled children (CMO 2012). For example reducing the number of children who live in damp, poor quality housing will reduce admissions to hospital for respiratory infections.

5.2.2 Health

GPs have an important role in supporting the disabled child and their parents/carers. The CMO's annual report (2012) suggested that children with disabilities and/or long-term conditions, should be recognized as vulnerable people, and as such should have a named GP who co-ordinates their disease management.

There is a strong link between obesity and disability in children and young people; reducing obesity in disabled children will minimize the impact of their disability and better enable them to participate in daily life. Parents/carers, schools and communities can support disabled children to maintain a healthy weight by reducing barriers to participation in physical activity including sport. Evidence shows that regular physical activity provides important health benefits for people with disabilities. Benefits include improved cardiovascular and muscle fitness, mental health, balance, and a better ability to do tasks of daily life (CDC 2016). Children and young people with SEND, including long-term conditions such as diabetes, have an increased risk of low social and emotional wellbeing than children and young people without SEND. Whilst some of this risk is related to the underlying condition, such as the anxiety associated with autism, other risk factors include being socially excluded and/or bullied. Young people who had reported being bullied had lower Key Stage 4 scores than other young people and were also more likely to leave full time education at the age of 16, and were likely to be NEET (Not in Education, Employment or Training) (Green et al 2010). In addition, Children and young people with SEND are more likely to experience mental health problems and more likely to need intervention by specialist services.

Some children and young people with SEND will need specialist support from Speech and Language Therapists (SALT) to develop their speech, language and communication as undetected and/or untreated speech language and communication problems can lead to low levels of literacy, poor educational attainment and difficulties finding employment (Royal

College of Speech and Language Therapists 2011). For children with complex needs SALTs play a vital role in working directly with the child within school as well as supporting the teachers and teaching assistants to differentiate the curriculum appropriately. Some conditions, such as autism, particularly benefit from SALT support (NICE 2011).

5.2.3 Education

The SEND code of practice (2105) is a framework for best practice, identification and provision of services for children and young people with SEND. Parents, children and young people should feel able to tell their school or college if they believe they have or may have SEN in order to access additional support. In addition, a child's parents, young people, schools and colleges have the right to request a needs assessment for an education and health care plan (EHCP).

All children and young people should expect to receive an education that enables them to achieve the best possible educational and other outcomes, and become confident, able to communicate their own views and ready to make a successful transition into adulthood, whether into employment, further or higher education or training.
Underpinning this are a range of statutory duties on schools, described below.
All mainstream schools have a duty to use their best endeavours to provide support to children and young people with SEN, whether or not they have an EHC plan. They must designate a teacher to be responsible for co-ordinating SEN provision (the SEN co-ordinator or SENCO) and must inform parents when they are making special educational provision for a child.

All staff should have the training and skills to support children with SEN in their classroom through quality first teaching. The needs of pupils with SEN should be included in all strategic planning and development.

Mainstream schools must ensure that children and young people with SEN can take part in the activities of the school alongside those who do not have SEN, and maintained schools and academies must make arrangements to support those who have medical conditions

All pupils should have access to a broad and balanced curriculum. Careful planning of lessons to address potential areas of difficulty and to remove barriers to pupil achievement

will mean that, in many cases, pupils with SEN and disabilities will be able to study the full curriculum.

All schools have duties under the Equality Act 2010 towards individual disabled children and young people. They must make reasonable adjustments, including the provision of auxiliary aids and services for disabled children, to prevent them being put at a substantial disadvantage. These duties are anticipatory – they require thought to be given in advance to what disabled children and young people might require and what adjustments might need to be made to prevent that disadvantage. Schools also have wider duties to prevent discrimination, to promote equality of opportunity and to foster good relations.

There should be a member of the school's governing body or a sub-committee with specific oversight of the school's arrangements for SEN and disability. School leaders should regularly review how expertise and resources used to address SEN can be used to build the quality of whole-school provision as part of their approach to school improvement and tracking of pupil progress.
Maintained schools and academies must prepare an SEN information report and their arrangements for the admission of disabled children, the steps being taken to prevent disabled children from being treated less favourably than others.

Schools and Pupil Referral Units must ensure that from year 8 to year 13 pupils are provided with independent career guidance.

5.3 Condition specific evidence

NICE Guidance

QS39 Attention deficit hyperactivity disorder: Diagnosis and management of ADHD in children, young people and adults (2016)

Many children with ADHD may also have SEN. When a child or young person with disordered conduct and suspected ADHD is referred to a school's special educational needs coordinator (SENCO), the SENCO, in addition to helping the child with their behaviour, should inform the parents about local support including parent education programmes. Professionals, with the parents' consent, should contact the teacher to explain any special educational needs.

CC128 Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum (2011)

This guidance demonstrates the local pathway for recognition, referral and diagnostic assessment of possible autism and seeks to improve the experience of autistic children, young people and those who care for them. The evidence underpinning the guidance has been reviewed in 2016 and the guidance will be updated accordingly.

CG170 Autism: The management and support of children and young people on the autism spectrum (2013)

This guidance highlights the different ways that health and social care professionals can provide support, treatment and care for children and young people with autism, and their families and carers, from early life through to their transition into adult life. The guidance includes specific interventions for challenging behaviour, life skills alongside general principles of care. In addition it highlights interventions that should not be used in autism.

5.4 Transition

NG43 Transition from children's to adults' services for young people using health or social care services

This guideline incorporates the period before, during and after a young person moves from children's to adults' services. It aims to improve young people and their parents/carers experience of transition by improving the way transition is planned and carried out. It covers both health and social care[11]. It emphasises the importance of young people having the right to be involved in discussions and make informed decisions about their care.

The Doran Review (2012)[12] highlights the right of every child to become a successful learner, confident individual, effective contributor and responsible citizen recognising that some children will face barriers to learning and need additional support to enable them to realise their potential. The review states:

> *"Effective management of transitions from one stage of education to another and on to life after school is a key component to effectively meeting the needs of all children and young people. It is crucial when considering any changes for those children and young people with complex additional support needs."*

[11] Transition: Getting it Right for Young People – Improving the transition of young people with long-term conditions from children's to adult health services, Department of Health and Department for Education and Skills (2006)
[12] The Doran Review 2012: The Right Help at the right time in the right place

5.5 Health and wellbeing

In addition; many of the issues faced by children and young people with SEND and their families are broadly similar to those faced by those without SEND and already have dedicated chapters within other JSNA's.

These include:

- Avoidable injuries in children (2015)
- Child poverty (2012)
- Children in care (2013)
- Dental health in children and young people (2009)
- Diet and nutrition (2011)
- Obesity (2012)
- Early years (2016)
- Emotional and mental health needs of CYP aged 0-18 (2015)
- Pregnancy (2015)
- Substance misuse in children and young people (2012)

6) What is on the horizon?

- The number of children and young people aged 15 years and under is projected to increase by 2,700 by 2020 reflecting the recent increase in birth rate (ONS Mid 2012 population projections). If the proportion of disabled children in the population (3-5.4%) remains stable between 80 and 146 of these children/young people will have disabilities. This estimate does not include children arriving in Nottingham from Europe and further afield.

- The percentage of the population in BME groups is likely to continue to rise. It is likely that the disabilities which are more common in some BME groups will rise at a similar rate e.g. disabilities due to co-sanguinity. In addition, children born outside the UK who haven't had access to early treatment and intervention in their country of birth may require more intensive therapies to realise their potential.

- It is challenging to correctly identify the number of children and young people with severe and complex disability as there is no single data source that collates this information. Thus it is challenging to project how the numbers of these children and young people will change and thus how services will adapt to meet their needs.

- The prevalence of conditions that result in reduced life expectancy is increasing; due in part due to improved survival of pre-term, very low birth-weight babies. Specialised

services, such as palliative care services, will need to increase in parallel to meet the needs of these children.

- Medical advances mean that children and young people with complex conditions are living longer (DfE 2014). For example, the likelihood of a child/young person with Duchenne muscular dystrophy living to the age of 25 rose from 12% in the 1980s to 53% by 2002 and new therapies are leading to further increases in lifespan (Eagle et al 2002). Services will need to change and adapt to ensure adequate provision for their needs.

- Austerity measures are disproportionally likely to affect families with disabled children[13]. Service reductions may lead to delays in diagnosing conditions for which there is evidence that early intervention makes a positive difference and increased risk of complications where timely identification and intervention could have made a positive difference.

- The number of EHCP/statements in Nottingham is increasing compared to a small decrease nationally. It is unclear whether this is due to an increase in children/young people whose needs indicate an EHCP/statement is warranted or system/process changes.

- The implementation of proposals within the current education white paper, *Educational Excellence Everywhere,* may have a significant effect on the identification and support processes for pupils with SEND. The LA will retain statutory responsibilities for pupils with an EHCP. However, multi-academy trusts (MATs) will have an increasing level of responsibility for identification and provision for pupils at SEN Support, so that a new relationship must develop between the LA and MATs to ensure that the requirements of the SEN Code of Practice continue to be met and appropriate provision made.

7) Local Views

In 2015 parent/carers were consulted as part of the SEND review. Questions were broad and included the age of children, type of need, services accessed over the past 12 months

[13] Survey of BACCH and BACD members and Child Development Team leads November 2014 and January 2015

and levels of satisfaction. 158 responses were received from parents/carers of children with a wide range of SEND including physical disabilities, ASD and behavioural difficulties.

Parents and carers suggested that whilst Nottingham has a good range of highly valued services we still assess far too much. The barriers between health and social care were noted as being particularly frustrating. Direct payments were seen as a useful way of accessing the support their son/daughter needed.

50% of parents/carers who responded felt they had insufficent information to make informed choices with only 13% stating they used the SEND local offer website. In line with national research, parents/carers noted that they needed to be 'pushy' to get the services they needed for their son/daughter.

Problems in accessing speech and language therapy was noted by a number of parents/carers. One stated:

> *"There is no SALT anywhere. My child is non-verbal and hasn't seen and can't get to see any speech therapy."*

Transition support was described as 'patchy' particularly for young people with SEND who attended mainstream schools.

62 children and young people with SEND who were consulted described the activities they enjoyed and the actions they took to be healthy such as dancing. They noted that some websites, aimed at them, were too busy and thus difficult to use. It appeared important that people who knew them well were around to offer support be that in health or education. A number of children/young people noted that their parents/carers knew them best and were thus their best source of support.

Parents and carers on the whole were positive about the services that their children received. As well as providing a scored judgement, parents also added additional comments including the following:

> *"My child received support from the Disabled Children's team who were amazing and gave support when it was needed. …My child benefited from activities so much."*

“Paediatrician - very open to helping with additional services e.g. SALT referral and transition to adult services being planned.”

“Oakfield School is fantastic, my son enjoys it compared to the main stream where he was in a corridor all the time and never played outside. Here at the school everyone knows the children … they helped me arrange things round my son.”

“Occupational Therapy are amazing, full of energy and enthusiasm and very helpful with suggestions. They are really taking time to get to know my child and find ways to support him.”

“City Hospital children's physio department are amazing, so supportive of my girls as well as myself; they have gone above and beyond to help us.”

“Disabled Children's team are always on hand if there are any problems. Crocus Fields are great with the kids and help with their independence. Fundays are great for keeping busy in the summer holidays. Paediatrician - very open to helping with additional services e.g. SALT referral and transition to adult services being planned GP - good family doctor relationship already developed ready for adult services transition.”

What does this tell us?

8) Unmet needs and service gaps

- Feedback from parents/carers and professionals suggests that there are significant challenges in accessing Speech and Language Therapy (SALT) in Nottingham. Data suggests that there are more children and young people with autism in Nottingham than the England average; autistic children are particularly likely to need SALT.

- Feedback from parents suggests that there is a lack of information regarding SEND provision. It is unclear whether lack of use relates to lack of awareness of the SEND Local Offer website or the functionality of the website itself.

- Evidenced based interventions early in life can improve outcome for disabled children yet not all children in Nottingham access early support services.

- Not all children with SEND are vaccinated as recommended which makes them vulnerable to infectious diseases which can be more serious for those who also have physical disabilities. In addition, some disabilities are associated with vaccine preventable diseases such as birth defects due to congenital rubella syndrome or encephalitis following measles.

- Local intelligence suggests that children and young people with SEND sometimes miss out on health promotion interventions such as school-based sessions on sex and relationships and/or smoking, drugs and alcohol even though these sessions could be adapted to meet their needs.

- Parents report that SEND support varies from school to school. Whilst many schools are committed to supporting children and young people with SEND parents reporting that some school staff lack appropriate knowledge and skills which hinders their ability to fulfil their potential.

- The range of short breaks available to disabled children and young people is limited and is not always sufficiently tailored to meet individual needs.

- Literature[14] suggests that there is an under representation of some ethnic minorities in diagnosis of SEND e.g. autism. It is unclear whether this is this due to lack of awareness within these communities, stigma around disability or professionals not diagnosing in these groups.

- Consanguinity is a significant risk-factor for some disability. It is unclear whether more action could be taken to highlight the risk to relevant communities.

- The process of assessment can lead to a focus on what children and young people with SEND can't do rather than what they can achieve, particularly, when they have the support of their family and community.

- Children, young people and families report feeling isolated in part as they struggle to access activities in their local community.

- There is less transition support for young people with SEND who do not have an EHCP/statement and/or don't meet social care thresholds for support. For these young people the support is managed by the school without little additional support from outside agencies. This does not meet NICE guidance on transition.

- There are low levels of employment for people with learning disabilities. It is unclear why Nottingham has a significantly lower proportion of people with learning disabilities in employment that the England average. Incomplete tracking of young people post-19 is a barrier to understanding which strategies are successful in supporting young people with learning disabilities into work.

- Whilst considerable action has been taken people with learning disability are still in healthcare institutions as adults. This is unacceptable.

9) Knowledge gaps

- There is a lack of accurate local, and national, data on the number of CYP with disabilities especially severe and complex disabilities which hinders effective planning of services to meet their needs.

[14] http://www.ncbi.nlm.nih.gov/pubmed/18600440

- The data on the destinations of young people SEND after 19 years of age is scant. Without this data agencies are unable to establish effectiveness of commissioned services across health, education and social care.

- Whilst a plethora of information is available it is still challenging for parents/carers to choose a school appropriate for the needs of their child. For example, how does a parent/carer ascertain the level of knowledge of the teachers and teaching assistants in supporting pupils with SEND?

- Ethnicity is poorly recorded by many services in Nottingham; without accurately understanding the ethnicity of children and young people with SEND agencies are unable to assess equity of access and outcome.

- The primary SEND need of autism in Nottingham is higher than the England average. Local intelligence suggests that this could be related to lower levels of SLCN which is often identified prior to a diagnosis of autism.

- The implementation of proposals within the current education white paper, “Educational Excellence Everywhere” may have a significant effect on the identification and support processes for pupils with SEND.

What should we do next?

10) Recommendations for consideration by commissioners

- There appears to be significant challenges in accessing Speech and Language Therapy (SALT) in Nottingham despite high numbers of autistic children who are particularly likely to need SALT. Benchmarking of SALT provision against national guidance, exploration of the current provision and a health equity audit could inform future commissioning decisions.

- Feedback from parents suggests that there is insufficient information regarding SEND provision. Further work with the Communications team, informed by feedback from parents, will give children, young people and their families greater control through the provision of comprehensive and accessible information about the range of educational placements and support available, curriculum choices and alternative pathways.

- Continue to develop and improve the *Local Offer*, working with children, young people and their families to ensure the information is comprehensive and accessible.

- Provide support to children and families in the home and early years settings to promote early intervention and improved outcomes through well-co-ordinated early support services, so that parents have increased understanding and raised aspirations for their children and that admission to school is supported by personalised transition processes, resulting in effective inclusion of pupils in chosen educational placement.

- Predicted increases in the number of children and young people with SEND should be incorporated into forward planning of children's services. Modelling of these increases will more accurately inform service planning. For example services for extremely premature babies and those surviving longer with more complex needs.

- Some children and young people with SEND will be more vulnerable to infections and thus have an increased need for vaccination. All those working with this group could use a 'make every contact count' approach to encourage vaccination, specifically, to correct purveying myths around the safety of vaccinations such as MMR.

- Local intelligence suggests that children and young people with SEND sometimes miss out on health promotion interventions such as school-based sessions on sex

and relationships and/or smoking, drugs and alcohol even though these sessions could be adapted to meet their needs. A review of this provision could ensure that children and young people with SEND have equity of access to sessions that enable them to make informed decisions.

- Education support services will continue to work in partnership with schools to ensure they understand the requirements of the SEND Code of Practice, and have the knowledge and understanding needed to support the effective implementation of the legislative requirements. Further development of the links between special provision and mainstream schools will extend the good practice, knowledge and expertise available across all settings, as part of on-going CPD opportunities for teachers and support staff.

- Raise educational achievement of children and young people with SEND through early identification of need, appropriate intervention and effective monitoring of progress towards challenging targets.

- Continue with Nottingham city's plan to convert statements to EHCP by 2018. The City is on target to convert all statements to EHCP's by August 2017. This activity will ensure that all young people and families will have access to the benefits of the EHCP including personal budgets where relevant.

- Review the role of the key worker service in supporting the implementation of EHCPs. This review will ensure that the best aspects of the service are retained and that the service is sustainable in the longer term.

- The range of short breaks available to disabled children and young people is limited and is not always sufficiently tailored to meet individual needs. A broad range of short breaks should be developed to include those delivered through internal provision, commissioned services and purchased through personal budgets.

- Conduct a review of the contract carers scheme to ensure family based overnight short breaks can be provided for children and young people with a range of disabilities.

- Literature[15] suggests that there is an under representation of some ethnic minorities in diagnosis of SEND e.g. autism. It is unclear whether this is this due to lack of awareness within these communities, stigma around disability or professionals not diagnosing in these groups. Further exploration of this under-diagnosis is warranted.

- Nottingham's population is diverse; services may need to be adapted to meet the cultural needs of different communities to ensure equity of access and outcome.

- Consanguinity is a significant risk-factor for some disability. It is unclear whether more action could be taken to highlight the risk to relevant communities and to mitigate risk, through genetic screening, where there are known risks.

- Work in partnership with communities to take an asset based approach to children and young people with SEND focusing on what they can do, what family and friends can do, and only then what services are needed, to help people to live their lives.

- Ensure disabled children and adults aren't isolated from mainstream society through a comprehensive local offer which enables children and young people to access a range of mainstream/targeted/specialist activities where they are able to meet socially with their peers in an inclusive environment.

- Children, young people and families report that their experience of transition between services can be unnecessarily challenging. By conducting joint assessments parents/carers won't have to repeat their story to multiple professionals. In addition pooled, personal budgets (social care and health) could minimise duplication of assessment and payment processes.

- Ensure that disabled children's transition into adulthood is properly supported. Specifically, transition should be improved for children and young people with SEND who do not have an EHCP/statement and/or do meet the threshold for adult social care support.

[15] http://www.ncbi.nlm.nih.gov/pubmed/18600440

- Many young people with SEND feel ill-prepared for adult life and unable to achieve their ambitions. Early years settings, schools and colleges should enable children and young people to have the information and skills they need to gain independence, transition to adulthood and achieve their ambitions including gaining meaningful employment.

- The tracking of the destinations young people with SEND after their 19th birthday should be improved to increase understanding of what pathways are working, which need developing and which should be decommissioned.

- Whilst considerable action has been taken people with learning disability are still in healthcare institutions as adults. Further action needs to be taken to enable disabled people to live at home, near home or in independent living of their choice.

- Joint commissioning and/or pooled budgets have the ability to minimise duplication of effort and release cost savings that can be invested elsewhere. Nottingham City Council and Nottingham City CCG could explore joint commissioning opportunities for children and young people with SEND.

- Commission appropriate IASS provision to meet the needs of children, young people and families within the Codes of Practice including through the development of a robust specification that meets the needs of all service users and the extended requirements of the Act in the longer term – unclear Clare please advise or we can remove. We haven't highlighted this as a problem in the document.

- There appears to be significant challenges in accessing Speech and Language Therapy (SALT) in Nottingham despite high numbers of autistic children who are particularly likely to need SALT. Benchmarking of SALT provision against national guidance, exploration of the current provision and a health equity audit could inform future commissioning decisions.

Key contacts

Helene Denness, Consultant in Public Health, Nottingham City Council
helene.denness@nottinghamcity.gov.uk

Clare Gilbert clare.glibert@nottinghamcity.gov.uk

Charlotte Reading charlotte.reading@nottinghamcity.gov.uk

References

BEGEER, S., et al., 2009. Underdiagnosis and referral bias of autism in ethnic minorities. Journal of Autism and Developmental Disorders, 39(1). 142-8.

BLACKBURN, C. M., SPENCER, N.J., READ, J.M., 2010. Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey. BMC Pediatrics, 10(21).

BLACKBURN, C. M., SPENCER, N.J., READ, J.M., 2013. Is the onset of disabling chronic conditions in later childhood associated with exposure to social disadvantage in earlier childhood? a prospective cohort study using the ONS Longitudinal Study for England and Wales. BMC Pediatr, 13(101).

CENTRES FOR DISEASE CONTROLL AND PREVENTION., 2016. Increasing Physical Activity among Adults with Disabilities [online]. Atlanta, GA: CDC. Available at: <URL: http://www.cdc.gov/ncbddd/disabilityandhealth/pa.html>

CHEN, X., et al., 2007. Teenage pregnancy and adverse birth outcomes: a large population based retrospective cohort study. International Journal of Epidemiology, Issue 36, 368-373.

CHIMAT., 2011. Disability and obesity: the prevalence of obesity in disabled children [online]. London: ChiMat. Available at <URL: https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&cad=rja&uact=8&ved=0ahUKEwjoqLed_8fNAhUSM8AKHTetAgsQFggnMAE&url=http%3A%2F%2Fwww.chimat.org.uk%2Fresource%2Fview.aspx%3FRID%3D115188&usg=AFQjCNFVLjtv7_RFkJAFSiuMYfqKyzaeVA&sig2=9rFPsTyO1G5GSZzk3UVSrA&bvm=bv.125596728,d.ZGg>

DEPARTMENT FOR EDUCATION AND SKILLS; 2007. Aiming high for disabled children: better support for families. London: Department of Education and Skills

DEPARTMENT FOR EDUCATION, 2014. Special educational needs and disability: Research priorities and questions [online]. London: Department for Education. Available at <URL: http://dera.ioe.ac.uk/19698/1/SEN_Research_Priorities_and_Questions_Final_Draft.pdf>

DEPARTMENT FOR EDUCATION., 2010. Ethnic disproportionality in the identification of speech language and communication needs (SLCN) and autism spectrum disorders (ASD): 2005-2011. London: Public Health England.

DEPARTMENT FOR EDUCATION., 2011. Support and aspiration: a new approach to special educational needs and disability. London: Department for Education.

DEPARTMENT FOR EDUCATION., 2016. Absence and exclusions additional analysis for pupils with special educational needs (SEN). London: Department for Education.

DEPARTMENT FOR EDUCATION., DEPARTMENT OF HEALTH., 2015. Special educational needs and disability code of practice: 0 to 25 years - Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities [online]. London: Department of Education. Available at: <URL:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf>

DEPARTMENT FOR WORK AND PENSIONS., 2013. Fulfilling Potential: Building a deeper understanding of disability in the UK today [online]. London: Department for Work and Pensions. Available at <URL: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/320509/building-understanding-main-report.pdf>

DEPARTMENT OF HEALTH., 2014. Refreshing the NHS Outcomes Framework 2015-2016 [online]. Available at <URL:https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/341391/14-07-30_NHS_Outcomes_Framework_Stakeholder_Engagement_Document.pdf D>

EAGLE, M., 2002. Survival in Duchenne muscular dystrophy: improvements in life expectancy since 1967 and the impact of home nocturnal ventilation. Neuromuscular Disorders, 12(10). 926-9.

EARLY INTERVENTION FOUNDATION., 2016. What is Early Intervention? [online]. London: Early Intervention Foundation. Available at <URL: http://www.eif.org.uk/what-is-early-intervention/>

EMERSON, E., 2010. Deprivation, ethnicity and the prevalence of intellectual and developmental disabilities. Journal of Epidemiology and Community Health.

GOULD, J., ASHTON-SMITH, J., 2011. Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum. Good Autism Practise, 12(1), 34-41.

GOV.UK., 2015. Two in every five London children are not school ready by age 5 [online]. London: Gov.uk. Available at <URL: https://www.gov.uk/government/news/two-in-every-five-london-children-are-not-school-ready-by-age-5>

GREEN, R., et al., 2010. Characteristics of bullying victims in schools. London: Department for Education and National Centre for Social Research.

HESLOP, P., 2013. Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) :Final report. London: CIPOLD.

HM GOVERNMENT., 2010 . Equalities Act 2010: Explanatory Notes [online]. London: HM Government. Available at: <URL:http://www.legislation.gov.uk/ukpga/2010/15/notes/division/2>

HM GOVERNMENT., 2013. Annual Report of the Chief Medical Officer 2012. London: Department of Health.

HM GOVERNMENT., 2014. Children and Families Act 2014 [online]. London: HM Government. Available at <URL: http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

HOLLOMON, H.A., DOBBINS, D.R., SCOTT, K.G., 1998. The Effects of Biological and Social Risk Factors on Special Education Placement: Birth Weight and Maternal Education as an Example. Research in Developmental Disabilities, 19(3). 281-94.

KIRKOVSKI, M., et al., 2013. A Review of the Role of Female Gender in Autism Spectrum Disorders. Journal of Autism and Developmental Disorders, 43(11).

LINDSAY, G., PATHER, S., STRAND, S., 2006. Special Educational Needs and Ethnicity: Issues of Over- and Under-Representation. London: Department for Education and Skills and University of Warwick

MARIE CURIE CANCER CARE., et al., 2012. Don't let me down: Ensuring a good transition for young people with palliative care needs [online]. London: Marie Curie Cancer Care. Available at <URL: https://www.mariecurie.org.uk/globalassets/archive/www2/pdf/dont-let-me-down.pdf>

MOONEY, A., et al., 2008. Disabled Children: Numbers, Characteristics and Local Service Provision. London: Department for Children, Schools, and Families.

MOORE, T., et al., 2012. Neurological and developmental outcome in extremely preterm children born in England in 1995 and 2006: the EPICure studies. British Medical Journal, Issue 345. 1 – 13.

MSALL, M.E., et al., 1992. Risk factors for major neurodevelopmental impairments and need for special education resources in extremely premature infants. J Pediatr, 120(5). 838.

NATIONAL FRAGILE X FOUNDATION., 2016. Autism Spectrum Disorder and Fragile X Syndrome [online]. Washington DC: National Fragile X Foundation. Available at <URL: https://fragilex.org/fragile-x/fragile-x-syndrome/autism-and-fragile-x-syndrome/>

NICE., 2009. Reducing differences in the uptake of immunisations (including targeted vaccines) among children and young people aged under 19 years. London: NICE

NICE., 2010. Strategies to prevent unintentional injuries among children and young people aged under 15. London: NICE.

NICE., 2016. Transition from children's to adults' services for young people using health or social care services [online]. London: NICE. Available at <URL: https://www.nice.org.uk/guidance/ng43>

OFSTED., 2010. The special educational needs and disability review. London: OFSTED.

PARSONS, S., PLATT, L., 2013. Disability among young children: prevalence, heterogeneity and socio-economic disadvantage. London: Centre for Longitudinal Studies.

PORTER, J., et al., 2008. Disability data collection for children's services - DCSF Research Report DCSFRR062. Bath: Department of Children, Schools, and Families.

PUBLIC HEALTH ENGLAND., 2014. Measles, mumps, rubella (MMR): use of combined vaccine instead of single vaccines [online]. London: Public Health England. Available at <URL: https://www.gov.uk/government/publications/mmr-vaccine-dispelling-myths/measles-mumps-rubella-mmr-maintaining-uptake-of-vaccine>

PUBLIC HEALTH ENGLAND., 2015. The determinants of health inequities experienced by children with learning disabilities. London: Public Health England.

RCPCH., 2015. Looked after children (LAC) [online]. London: RCPCH. Available at <URL: http://www.rcpch.ac.uk/LAC>

RCSLT., 2011. Guidance on Quality Standards for Local Authorities and Schools as Commissioners of Speech and Language Therapy Services in the UK. London: RCSLT.

RIZK, F., SALAMEH, P., HAMADE, A., 2014. Congenital Anomalies: Prevalence and Risk Factors. Journal of Public Health, 2(2). 58 – 63.

ROYAL COLLEGE OF NURSING., RCPCH., 2015. Looked after children: Knowledge, skills and competences of healthcare staff - INTERCOLLEGIATE ROLE FRAMEWORK. London: Royal College of Nursing and the RCPCH.

SHERIDAN, E., et al., 2013. Risk factors for congenital anomaly in a multiethnic birth cohort: an analysis of the Born in Bradford study. Lancet, 382(9901). 1350-9.

SUN, Y., et al., 2008. Gestational Age, Birth Weight, Intrauterine Growth, and the Risk of Epilepsy. American Journal of Epidemiology, 167(3). 262-70.

TEEUW, M. E., et al., 2013. Consanguineous marriage and reproductive risk: attitudes and understanding of ethnic groups practising consanguinity in Western society. European Journal of Human Genetics, Issue 22. 452-7.

THE ARK., 2016. Causes and Prevention of Intellectual Disability [online]. Washington DC: The Ark. Available at <URL: http://www.thearc.org/what-we-do/resources/fact-sheets/causes-and-prevention>

WORLD HEALTH ORGANISATION., 2016. Congenital Anomalies [online]. Geneva, Switzerland: World Health Organisation. Accessed at <URL: http://www.who.int/mediacentre/factsheets/fs370/en/>

Appendix 1

- Pathway 1: An application is made via the Short Breaks Team Manager.

  The child is in receipt of higher rate care or mobility component of DLA and the child has not been able to access the local offer even with inclusion support

- Pathway 2: An application is made via the Team Manager of the Disabled Children's Teams.

  The child has, as a result of their disability, a significant level of challenging behaviour that is likely to lead to self-harm or be injurious to others. The child is a permanent wheelchair user or has complex lifting and handling needs in addition to other social care needs. It is proposed that Pathway 2 will be aligned with Pathway 1 and will not require social work intervention

- Pathway 3: An application is made via the Service Manager, Disabled Children's Service.

There is more than one disabled child in the family. There is an adult member of the household with either a significant impairment or chronic ill health requiring significant support from the child's primary. The child has complex physical needs requiring regular care throughout the day and night. The child has a significant level of challenging behaviour that is likely to lead to self-harm or be injurious to others and requires regular supervision during the day and night.

- Pathway 4: An application is made via the Continuing Care and Complex Needs Panel.

  The child cannot be maintained safely due to their disability in the community. A carer is required to provide 24/7 care. End of life care is needed.