

Children and Young People Special Educational Need and Disability

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Executive summary	

Introduction

This chapter considers the health and education needs of children and young people, 0 to 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 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 not 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.