

## Children with Disabilities and/or Special Educational Needs - February 2012



### A Needs Assessment for Nottinghamshire Executive Summary



"I am very grateful for the respite and play services my son receives and would feel far less anxious if I could be assured that planners were assessing needs for the growing population.....coming through the system and that provision, recruitment and training of staff should be happening now to meet their needs once they reach adulthood."

**Local parent**



## Introduction

The Nottinghamshire Children's Trust has developed this needs assessment to identify the needs of children, and young people with disabilities and/or Special Educational Needs (SEN) and their families within the county. Findings from this needs assessment will be used to influence a local joint commissioning strategy, which will make sure that the partner agencies work together, align resources to deliver their services effectively, provide good value for money and improve the experience and outcomes for people who use these services.

Establishing joint commissioning arrangements and processes around key target groups such as disabled children and young people will help to improve co-ordinated packages of support, streamline processes, reduce duplication and costs, as well as improve outcomes.

We are working to achieve the following ambition:

We want Nottinghamshire to be a place for everyone to enjoy a good quality of life and realise their potential; and for our children to be safe and happy. In particular we want children with a disability and/or special needs to have the same access of opportunity as other children, to aspire, and be empowered to do so.

To achieve this ambition we are working with partners to identify the needs of children, young people and families with disabilities in Nottinghamshire, we will identify gaps in service provision, review what children and families tell us and ensure our interventions and services are based on evidence based practice to improve outcomes.

Every child deserves a fair start in life, with the very best opportunity to succeed. Currently, life chances for the approximately two million children and young people in England who are identified as having a special educational need, or who are disabled, are disproportionately poor<sup>1</sup>.

"The assessment of children and families' needs and the development of services to meet those needs are vital steps towards well being. Having a complete picture of the numbers and circumstances of disabled children is part of this process, yet there is no current complete information in the UK to guide local areas."<sup>2</sup>

The data used in this needs assessment is based in the main on national and local estimates of needs, as well as data stemming from which groups access the services available locally. In addition, most children have more than one disability, with severely disabled children commonly having physical, sensory and learning disabilities. So planning which focuses on just one disability or the 'main' disability can be problematic.

It is also notoriously difficult to gather and analyse data on disability, as there is no comprehensive register of disabled

children in the county. Data is collected by numerous health and social care agencies, as well as education, and the different categories, definitions and thresholds used across the system add complexity to the process. For example, routine data is collected by local authorities on children with statements of special educational needs, but this does not reflect the spectrum of disability and is only a weak proxy measure for severity. Some agencies classify a 'young person' as being up to the age of 16, others up to 19, and others up to 25. In addition, information about individuals may be held in care records that are not linked, and even where data might be available, it is difficult to extrapolate and translate individual experiences into the population estimates needed for effective commissioning.

This needs assessment is therefore imperfect. It is a best effort, which contains incomplete data and gaps in information, synthetic estimates and 'educated guesses'. For example, data on school aged children is much more readily available than for children in the early years or post 16, so much more work needs to be done to 'drill down' into these areas. However, through the analysis of as much available intelligence as possible from a range of stakeholders, a picture of need has been formed, along with recommendations for more effective planning and commissioning.

There are a range of opportunities for joint work and joint commissioning for children and young people with SEN or disabilities. The development of this needs assessment is part of a phased approach and further information will be collected and analysed as the work is progressed and the strategy is developed and implemented.

## Aims of Needs Assessment

- To identify the population of children who have a disability in Nottinghamshire
- To understand the current demand for services alongside the current levels of provision
- To provide an evidence base and understanding of need for the forthcoming joint commissioning strategy
- To identify improvements in relation to data collection, analysis and use.

## Definitions

Nottinghamshire County Council and its partners have adopted the Disability Discrimination Act<sup>3</sup> (DDA) 2005 definition of disability:

"A child or young person is disabled if they have a physical or mental impairment which has substantial and long term adverse effect on his/her ability to carry out normal day to day activities"

## Methodology

This needs assessment was developed using information already available to a number of teams and organisations working in Nottinghamshire as well as national data and evidence. Researchers worked with members of the joint commissioning group to scope what information was required and then proceeded to work to answering a series of questions that commissioners and planners would find useful.

Researchers have also used qualitative information where available, including case studies and quotes from service users held by local organisations and teams.

## Key Headlines

The needs assessment highlighted the following headlines:

### Demography

- The national picture indicates that more children and young people with disabilities are living longer and surviving into adulthood.
- There are between 7,000 and 12,000 children and young people (0-19) experiencing some form of disability in Nottinghamshire. Indications are that this is slightly more prevalent among boys than girls.
- Nottinghamshire's overall 0-19 population is forecast to rise by 8.7% between 2011 and 2033, with the largest increase being in the 10-14 age group (20.2%).
- 20-24 year olds represent the highest proportion of young people with limiting long term illness (6.5%) in Nottinghamshire, followed by the 15-19 age group (5%). The lowest proportion is the 0-4 age group (2.7%).
- The highest number of young people (0-24) claiming Disability Living Allowance (DLA) live in Ashfield (1,380), followed by Mansfield and Newark & Sherwood (both 1,170 each). The lowest number live in Rushcliffe (640).
- There has been a 60% rise in young claimants (0-24) of DLA in Nottinghamshire over the last decade.
- One in five Nottinghamshire school pupils has some kind of special educational need (SEN). The highest rates are in Mansfield (24.1%), Ashfield (21.4%) and Bassetlaw (21.3%).
- Over the last five years, the percentage of SEN pupils in Nottinghamshire primary schools has decreased from 16.6% to 16.0%. However, in the county's secondary schools, the percentage has increased from 15.9% to 22.8%.
- Around 1,550 pupils in Nottinghamshire have been assessed as School Action Plus or Statemented, so have a primary need of behavioural, emotional or social difficulties (BESD) by schools, and 1,880 have some form of learning difficulty.

- National evidence indicates that black and minority ethnic families are less aware of, and make less use of, specialist disability services; and that asylum seeking families may not report their child's impairments for fear it might affect their immigration status.

## Themes

### Poverty

- National research shows that disabled children are more likely to live in poverty - the average income of families with disabled children is nearly a quarter less than the mean UK income.
- In Nottinghamshire, the rates for severe disability are greatest amongst children from 'semi-skilled manual' family backgrounds, with the lowest rates in the 'professional' and 'managerial' categories.
- A recent health needs assessment of Nottinghamshire (city & county) special schools also identified a strong relationship between level of need and deprivation. It is not certain if this is a reflection of actual prevalence of need, or ability to meet need due to resources available within the family.
- 13% of Nottinghamshire school pupils are eligible for free school meals. This figure more than doubles for pupils who are at School Action Plus or have a statement (28%).
- National evidence suggests that families with a disabled child are 50% more likely than other families to live in overcrowded accommodation, to rate their home as being in a poor state of repair and to report problems with wiring, draughts and damp in the child's bedroom.
- It is possible that those who are most in need of services are the least likely to access them due to the 'inverse care law', which suggests that those living in areas of deprivation find it more challenging to access services than their more affluent counterparts.
- National evidence suggests a lack of 'door to door' transport, either through school transport services or public transport, is a key barrier to participation in out of school opportunities and activities for many disabled children and young people.

### Social Care

- There are just under 100 school pupils in the county who are both the subject of a child protection plan and have an SEN category. Just under half of these (47%) have BESD.
- There are on average 75 looked after children (LAC) in Nottinghamshire who have a disability, with the highest numbers in Mansfield and Ashfield.
- The number of children (aged 5-15) who have been looked after continuously for at least 12 months and who have an SEN category totals 180 (or 74.5%

of that cohort). As there are approximately 20% of Nottinghamshire pupils overall with SEN, this means LAC are three and a half times more likely to have SEN compared to all pupils.

- So far in 2011 there have been 177 referrals to the County Council's Disabled Children's Team (up to November), compared to 325 in all of 2010 and 279 in all of 2009.
- In 2010/11, 260 disabled children and young people in Nottinghamshire accessed direct payments, up from 95 in 2007/08.
- Nottinghamshire pupils who are in the School Action Plus category are around 25 times more likely to have a Common Assessment Framework than non-SEN pupils.
- National data indicates that children with SEN and/or disabilities are disproportionately at risk of bullying. However, the number of disability hate crime incidents reported in Nottinghamshire is low.

### Early years and childcare

- The Disabled Children's Access to Childcare programme is currently supporting 168 children and young people (0-19). 96 of these are in the 0-4 age range.
- Children's centres in Nottinghamshire saw 410 disabled children (aged 0-4) between September 2010 and August 2011, compared to 216 in the previous twelve months.

### School Education

- The achievement gap at Key Stage 2 between SEN and non-SEN pupils in Nottinghamshire has narrowed over the last four years, but is slightly worse than statistical neighbours and the national average.
- At Key Stage 4, the gap in Nottinghamshire is better than statistical neighbours and the national average, but is widening as non-SEN pupils improve at a faster rate than SEN pupils.
- Children with SEN in Nottinghamshire have higher than average absences from school and are four times more likely than the rest of the school population to be persistent absentees. This is broadly in line with other local authorities.
- SEN pupils in the county are ten times more likely than the rest of the school population to receive a fixed period exclusion from school and nearly 15 times more likely to be permanently excluded.
- Over a quarter (27%) of children who are electively home educated in Nottinghamshire have special educational needs.
- There are 11 special schools in the county, which currently accommodate 847 pupils. 84 pupils who live in the county attend special schools in other local authorities and 103 pupils who live outside the county attend Nottinghamshire special schools. Placements in independent or non-maintained special schools have increased from 58 in 2005/06 to 132 in 2011/12.

- The most common high level needs in Nottinghamshire (city & county) special schools are personal care, physiotherapy, continence, communication, occupational therapy, wheelchair and moving/handling.
- County Council provision for home to school transport for pupils attending special schools and other school provision will account for around £5.7m in 2011/12, up from £4.7m in 2005/06.
- Children and young people with SEN in Nottinghamshire schools consulted in 2009 said they did not feel sufficiently engaged in decision making processes that affect them; that they are often the victims of bullying; and that the level of personalised learning in schools does not always match the diversity of their needs.

### Post-16 Education

- The biggest challenge commissioners face is to find suitable placements for a small number of young people with complex needs (mainly emotional/behavioural or Autistic Spectrum Disorder (ASD)), who have been engaged on alternative provision pre-16 (often one to one support) and therefore struggle to integrate into a mainstream or specialist post-16 placement.
- Young people in Nottinghamshire with learning difficulties and/or disabilities (LDD) are over-represented in NEET (not in education, employment or training), especially School Action Plus pupils.
- The proportion of Nottinghamshire residents aged 16-19 with LDD in further education and sixth form colleges is 22%, which is slightly above the regional average (19%).
- In the county in 2010/11, there were 49 residents aged 16-24 with placements in Independent Specialist Providers (ISPs), up from 38 in 2009/10. Nottinghamshire is one of six local authorities in the East Midlands with 50% or more of their residents in ISPs placed in residential rather than day provision.
- Between 2001/02 and 2010/11 there was a 72% increase in the number of accepted disabled UCAS applicants in Nottinghamshire (403 accepted in 2010/11), compared to a 16% increase in the non-disabled population.

### Caring Responsibilities

- Parents with disabled children are at increased risk of stress compared to other parents, and stress levels are strongly linked to child behaviour and sleeping problems.
- The numbers of children and young people accessing short breaks has increased from 860 in 2007/08 to 2,190 in 2010/11.
- Siblings can feel pushed out, may be jealous of the attention their disabled sibling receives and are often carers themselves - which can in turn affect their achievement at school, their general well-being and their own friendships.

- A national study of families with children with profound and multiple difficulties found that 60% of parents spend more than 10 hours per day on basic physical care. These demands can deter parents and carers from accessing employment.
- A different national survey identified that over nine out of ten family and friends carers who responded were grandparents.
- Local intelligence from the voluntary sector indicates that parents/carers sometimes do not know what support is available to them to help with transitions and how to access it. All parents consulted found transition planning a very difficult process and commented about the uncertainty they felt.
- Consultation with local families in 2009 indicated that services on offer do not always help with the complex 'juggling act' of looking after a family with a disabled child and that it is also difficult to find out what services are available.
- Other consultation locally undertaken in 2009 found that parents reported access to social and leisure opportunities for children and young people with SEN to be uncoordinated and frequently unavailable.
- Future growth in demand for specialist equipment is expected to accelerate given the increasing numbers of children with disabilities.
- An audit of 200 referrals to the Community Paediatric Service during 2010/11 identified that the highest proportion (50%) were as a result of problems with behaviour, such as ASD, ADHD and social interaction.
- The Paediatric Occupational Therapy Service received 105 referrals from the county (excluding Bassetlaw) and 62 from the City between April 2010 and September 2010.

## Conclusions

Improving the lives of disabled children and young people is a key priority for Nottinghamshire's Children's Trust. Representing a diverse group, disabled children often have highly complex needs requiring multi-agency support across health, social care and education services. Disabled children often require a vast and complex array of services, so they stand to benefit from joined up approaches to joint commissioning and planning.

The prevalence of severe disability is increasing because of higher survival rates of children and babies with some complex problems. Even if disability prevalence remains constant, the number of children with disabilities will continue to increase as the population of children and young people is forecast to grow. This needs assessment begins to identify some issues and encourages further work to forecast for increasing demands on services.

"Parents of children with disabilities experience vast variation in the kinds and levels of support they receive from a range of services, which appear to have little bearing on need."<sup>5</sup> This is reflected in the case studies and quotes included within this needs assessment where parents and carers are confused about what services their children are entitled to, what services are available; and what to do when support needs (real or perceived) are not met and the reasons for this. We have identified that there is some unmet need, however without having access to all data and performance information it is a challenge to identify exactly where unmet need is.

Substantial inequalities persist between disabled children and young people and their peers. This is an issue nationally and locally reflected within this needs assessment e.g. education outcomes.

There is a lack of current local information on the numbers of children and young people with disabilities and long-term conditions and the needs of this group; this has been compounded by challenges around data and information sharing across organisations. This has also made it a challenge to assess full levels of unmet need for disabled children and their families.

### Health

- It is difficult to identify the numbers of disabled children attending hospital due to the lack of a systematic way of recording status. However, one issue that has been identified is disabled children who spend prolonged periods in hospital with chest infections. A rapid response physiotherapy service is currently being piloted in the south of the county to treat this issue in the community - it is estimated that there are approximately 80-100 children and young people in the county (excluding Bassetlaw) who could benefit from the service.
- National data shows that children who have a limiting illness are more likely to be overweight or obese, particularly if they also have a learning disability. There is no local data on obesity and disability, as children unable to stand on scales are excluded from the National Child Measurement Programme.
- Children with physical or learning disabilities are identified nationally as at risk of not being fully immunised. There is, however, no local data on this.
- There are an estimated 1,800 children and young people (0-19) with ASD in the county. Diagnoses of ASD and demand on services are on the increase.
- NHS Continuing Healthcare in Nottinghamshire (excluding Bassetlaw) currently has 30 patients (aged 0-25) who receive fully funded continuing healthcare. In addition, during 2010/11, 27 items of equipment for patients (aged 0-25) were funded, with 17 items in the first six months of 2011/12.



Data is not always available but where it is we are not routinely sharing or analysing data for the benefit of service users. This results in children and families having to repeat their story too often and continued siloed working practices.

There are a substantial number of services which offer support and interventions to children and young people with varying levels of disabilities and/or SEN. There seems however often to be a lack of coordination of these services and interventions for families as services and teams often work very separately from each other.

This needs assessment is the tip of the iceberg as far more work is required to understand this subject appropriately to be able to influence service provision and working practices.

## Key Recommendations for Planners and Commissioners

### Top Six Priority Recommendations for members of the Joint Commissioning Group

1. The availability of relevant data would enable commissioners to more effectively commission services to meet the needs of this local population. Further work is required to further assess needs; in particular where data has not been made available for this needs assessment (further information is provided in later).
2. Ensure co-ordinated planning at all levels, with roles and responsibilities of different agencies clarified and understood by frontline staff working with young people.
3. Increase opportunities to integrate key services to ensure that there is a consistent approach, reduced duplication, improved efficiencies and clearer pathways for children, young people and families.
4. Increase joint commissioning opportunities to reduce silo working across agencies working with the same children and families.
5. Demand on services exceeds availability so budgets are tight, commissioners and services need to plan more together to be efficient and ensure needs led services and interventions developed and delivered jointly.
6. Use evidence based practice to shape local services and interventions, and help build the evidence base and invest time and resource into evaluation of interventions and processes.

### Additional Recommendations

- **Information sharing** - Removing barriers that prevent the sharing of data will enable joint commissioning whilst minimising duplication for children and young people,

families and service providers. Without more effective data-sharing, delivering integrated services will remain challenging.

- There should be more cross referencing of data sets to combine and explore data held by Nottinghamshire County Council, PCTs and NHS providers, Nottinghamshire Futures etc.
- **Improved data collection** - during the development of this needs assessment it has become apparent that organisations do not collect data that commissioners and planners would find useful, in particular measuring the impact of interventions on outcomes for children and young people with Disabilities and/or SEN. In addition mainstream services lacked data regarding disability e.g. apprenticeship schemes, and specialist services do not routinely collect data for service users including ethnic origin.
- Commissioners should be explicit about what data is collected and shared within contracts for all commissioned services working with these groups.
- Services and commissioners should look to develop improved monitoring which captures categories of disability need rather than just looking at primary or secondary needs in most cases. The Health Needs Assessment carried out in Special Schools provides a useful categorisation system.
- Data should be used to systematically plan and resource for evaluating the impact of what has been commissioned
- **Forecasting** - this needs assessment has identified there will be higher demand on services in the future. Commissioners and planners will need to ensure that forecasts are planned and resources available to meet increasing demand. In light of budget restrictions, planners may be required to review thresholds for some service provision to ensure those with greatest need are prioritised e.g. transport.
- **Improve the Nottinghamshire register of children and young people with a disability or SEN** - The register of all disabled children should be maintained by the Local Authority as they hold comprehensive education and social care information, improved information sharing with health partners is also critical. A comprehensive, up to date, and well used register is central to ensure a safe and responsive transition through key stages including early years to school, school to FE College, children's to adult services. It will also allow permission for data sharing across partners.
- Consistent requests for consent to share data should be a routine element of all initial contacts with families. Promoting the use of the register among a range of practitioners including healthcare who have early contact with target groups is fundamental to ensure children and young people's needs are identified and addressed in order to improve their outcomes. Data collected and

analysed through the register should be shared with front line practitioners so they understand the rationale for data collection.

- **Use evidence based practice** - this needs assessment identified evidence based practice to help improve outcomes for children with disabilities and/or SEN. A number of key areas have been included within these recommendations.
- It is also important however to help build the evidence base and invest time and resource into evaluation of interventions and processes.
- **Identification of Pre School disabled children** - Numbers of children aged 0-4 with a disability or SEN are often not known by services such as Children Centres. Health partners will hold more data on this population and it would be advisable if information could be routinely shared using the register of disabled children so that services can be targeted appropriately.
- **Increasing Numbers of SEN Young People** - explore why there are increasing numbers of young people assessed as having SEN in secondary schools in Nottinghamshire, and not in primary schools.
- **Assessing levels of unmet need** - A recent health needs assessment of special schools identified a strong relationship between level of need and deprivation. It is not certain however if this is a reflection of actual prevalence of need, or ability to meet need due to resources available within the family. It is important to remember that those living in areas of deprivation find it more challenging to access services than their more affluent counterparts. It would be useful therefore to carry out some qualitative work with families from different socio-economic groups to fully assess levels of need and unmet need.
- **Challenging behaviour** - Looking at children and young people's behaviour has been a challenge within this needs assessment because behaviour is not always linked to a clinical assessment or diagnosis and could be linked to a wide range of factors including parenting. Commissioners and planners need to be mindful of this issue when developing their joint commissioning strategy.

#### Intervention Approaches

- **Targeted interventions** - the needs assessment has identified that further work is required to ensure those with the greatest needs are targeted. It is important therefore to target children and families from the poorest socio-economic groups and key BME communities who we know are less likely to engage with some services.
- **Early intervention and prevention** - Understanding the causes of disability is critical for all Children's Trust partners, so the wider partnership can invest time and resource to support early intervention and prevention approaches e.g. maternal health (smoking, alcohol and substance use, folic acid) and prevention of infectious

diseases during infancy and childhood.

- **Lead Professionals** - Establish lead link/co-ordination roles for families requiring a range of interventions from a range of services. Children and young people who undergo a CAF will have a lead professional; however it is advisable for a lead professional role to support a whole family where there is a disabled child/young person, in particular those with complex needs. Improved partnership working is a necessity.
- **Participation of Service Users** - Listening to parents/carers and children/young people to help improve and plan services is critical to ensure those services meet identified needs. Evaluation practices must also routinely engage service users and target groups.
- **Early Years interventions** - evidence suggests that high quality pre-school centres improve children's cognitive development and reduce the need for special education in primary care. It would be useful to therefore assess the quality of early year's provision for children with disabilities or additional needs.
- **Direct Payments** - Analysis of feedback of parents and young people in receipt of direct payments should be sought and used routinely to understand any concerns, anxieties, barriers and support needs e.g. support as employers of their own staff.
- **Service/Care Pathways** - A number of service pathways are available for specific disabilities including ADHD, ASD, and Palliative Care. It is advisable that the joint commissioning group review these collectively to ensure pathways are clear and there are clear interrelations with a range of services across Nottinghamshire.

#### Information and Communication

- **Information, Advice and Guidance** - ensure clear non biased information, advice and guidance for parents and carers to help them to understand their rights, their entitlements, local services and how to access services for their children as well as support for themselves.
- Evidence suggests that web based information is the most effective in dealing with specific issues or problems.
- **Improved communication** - this needs assessment identified that in some cases parents and carers have higher expectations for services above and beyond what they can offer. Services need to be explicit about what they offer and to whom and when, this should be included on service materials as well as Nottinghamshire wide websites that target parents, carers and young people. It is also important for all professional groups to understand any recent changes to services including thresholds.
- In addition some parents and some professional groups do not understand why there are layers of bureaucracy before being granted approval for some services and

interventions. A greater understanding of the procedures surrounding the access to some services e.g. why a school may require written proof of a diagnosis, the processes and thresholds is urgently required.

- It is also important to ensure that parents, carers, children and young people understand why processes take time to complete by explaining to them what is involved, this is important at the start of processes but also throughout any process of assessment. Nevertheless if assessment processes are taking too long as identified by some parents in this needs assessment, then this should be remedied as soon as possible.

### Focusing on Outcomes

- **Measuring Outcomes** - many services have traditionally collected data on the numbers of service users seen and have not fully adopted service evaluation which captures the impact on the outcomes for children and young people. The forthcoming joint commissioning strategy should focus on improving outcomes and encourage improved evaluation and performance activity.
- **SEND Pathfinder** - It will be important for the Joint Commissioning group for children with disabilities and/or SEN to have a clear overview of the activity of the pathfinder to ensure learning influences practice e.g. the use of one assessment and one care plan shared by a range of organisations and professionals. This will also provide an opportunity to inform the evidence base of what works.

### Education Outcomes

- **Educational attainment** - further work is required to improve the attainment of children and young people who have a SEN statement and therefore close the gap between SEN children and young people and their peers at all key stages in particular Key Stage 4.
- Ensure that children and young people with disabilities and/or SEN are a key target group within the imminent 'Closing the Gap' strategy, in order to narrow the attainment gap.
- **Pupil Premium** - schools are due to receive the Pupil Premium which should help them to improve the attainment of the schools most disadvantaged pupils. It would be useful to ensure schools have access to evidence based practice on how best to use the resource for children and young people who are eligible for free school meals and have a disability or SEN.
- **Post 16 Educational Placements** - Information indicates that there are a range of services and interventions available for young people aged 16+ however the biggest challenge for many is to find suitable placements for a small number of young people with very specific complex needs. Many of these young people struggle to integrate into a college environment, mainstream or specialist post 16 placement. It is important to further develop the market to ensure

placements are available for these specific needs, as well as a review of the 2011/12 pilot programme which is using on-going support from the alternative pre-16 provider for four young people to support them to transition post-16.

### Health Outcomes

- **Occupational Therapy** - following on from the Joint Public Health and Social Care AHDC Occupational Therapy Pilot, there is still a need to develop a joint Occupational Therapy commissioning strategy with a clear pathway to provision in respect of equipment and other shared roles to ensure collaborative working and reduced confusion for families and therapists.
- **Improving access to specialist equipment** - Further discussions with health colleagues are required to agree a way forward to develop a fast track procedure/protocol for equipment (taking account of ICES criteria for provision).
- There need to be clear simple pathways for service users and professionals to help them understand roles and responsibilities for Occupational Therapy, Equipment Panels, ICES etc, this will also help ensure children and families know what to expect and who to contact.
- **Palliative care and Complex Health Needs** - a recent scoping report identified a number of recommendations that have yet to be implemented. These included the need for consistent provision of therapy services for this group of children and young people; the need for prompt referrals to community based services and increasing the availability of specialist family support and key working.
- There is also a requirement to develop flexible provision with a multi-skilled workforce that is county-wide, offering a range of services, including 24 hour on call, seven days a week support with the capability for home visiting for short breaks at end of life if required by families.

### Approaches to Joint Commissioning

- **Costs and benefits** - to enable improved joint commissioning and agreement of shared priorities, it would be useful to look at the costs of all key services and interventions. Commissioners should look to share this data so that cost benefit analysis work can be achieved, and decisions for commissioning priorities should explore value for money.
- An investment based model of joint commissioning should be adopted so that commissioners can assess value for money and cost benefit analysis.

### External Placements

- **Cross border working** - as has been identified in this needs assessment, Nottinghamshire pupils attend Special Schools outside of the Nottinghamshire County borders as other children attend Nottinghamshire schools from neighbouring areas. It would be worthwhile to assess how packages of support are agreed and funded for children and young people.



- **Out of Authority Placements** - Further work is required to understand who uses out of authority placements, why this placement was used rather than a more local service provision, why there are larger numbers being placed in these placements, feedback from children and young people, as well as cost implications. It would be useful to look at out of authority placements for children and young people using social care placements, special school placements and those in post 16 placements jointly.

### Transition Processes

- **Transition support** - It would be useful to widen the scope of research into support on transitions for all children and young people with SEN, for example children with dyslexia or young people moving into further education, training or employment. However it would be useful to gather specific qualitative information from children and families about transition.
- Transition services require greater collaboration across all key agencies to meet the priorities of young disabled people with complex needs as they move into adulthood.

### Equitable Access to Services and Interventions

- **Transport** - an urgent review of transport availability and use is required to ensure that those who need it most are able to access flexible transport, this however may mean that some universal transport provision will move to a needs assessed allocation in order to spread out already very thin resources.
- **Special School Nursing** - there seems to be currently some inequity in how Special School Nursing is delivered across Nottinghamshire Special Schools, further work would be required to ensure the service is equitable and based on need.
- **Short Breaks** - activity for children and young people to access short breaks seems to be responsive to need and the team is active in collecting and analysing information from service users. Work should continue to ensure those children and families most in need are prioritised for interventions.
- **Inclusive universal services** - All universal services need to be inclusive for children and young people with disabilities; this encourages children and young people to participate in activities with their peers and siblings and helps their understanding of peer culture. There should not be sole reliance on specialist activities. The use of access audits will help assess if services are inclusive.
- **Children Centres** - it is unclear if outreach targets for Children Centres in reaching disabled children are being met. It is known however that numbers seen at Children Centres are increasing; the interventions that took place in 2010/11 have had a positive impact on numbers seen by the centres. Further work should be implemented to ensure there is a continual increase in the numbers of disabled children accessing Children Centres. It would also be useful to identify the impact of Children Centre interventions on the outcomes of disabled children.

## Further Needs Assessment Activity

- **Ethnicity** - further work is required to ensure ethnicity data is collected by services as well as the register of disabled children, so that services can be prepared to meet a range of varying needs linked to ethnicity. We know for example that asylum seeker families are less likely to request support so organisations may be required to implement outreach activities to engage them.
- **Gender** - this needs assessment identified that more boys than girls are being assessed as having a disability. Additional work is required to explore this further and to understand gender differences e.g. are more boys than girls being identified as having challenging behaviour which has impacted on the data or is this linked to increasing diagnoses of ASD?
- **Locality of residence** - this needs assessment struggled to identify the geographical location of where disabled children and young people reside. Those in special schools however are known and data is available in Appendix Three, however further work is required to identify needs based on locality. This data may be available through better implementation of the register of disabled children and young people.
- **Social care data** - this data was not fully made available for this needs assessment so we lack information about how well social care support disabled children and their families in Nottinghamshire.
- **Out of authority placements data** - no data was provided for use in this needs assessment. It would be worthwhile to explore the numbers of children and young people in a range of out of authority placements, why they are there, how their needs are being met, and performance of these placements as well as cost. It is recommended that a further needs assessment is developed to look at this issue and include qualitative data from service users and their families.
- **Transition assessments** - Analysis of a range of data collected during core transition assessments would be useful for those responsible providing and commissioning services for children and families. Further work would be beneficial to collect, analyse and share this data with the joint commissioning group to enable them to have a greater understanding of issues for children and young people during key transition stages.
- **Qualitative feedback from children and young people** - although pre existing qualitative data was requested for this needs assessment, more information seemed to be available from parents and carers rather than the children and young people themselves. Any further needs assessment work must make every effort to engage children and young people with disabilities and/or SEN to gather their views of services and the issues facing them which impact on a range of outcomes.

- **Uptake of direct payments** - full data regarding the use of direct payments by parents of disabled children or disabled 16-17 year olds who access in their own right was not available for this needs assessment. It would be useful to explore data from health and local authority service leads to help to identify who accesses Direct Payments and who requires additional support. It would also be useful to see details of claimants e.g. age, gender, postcode.
- **Palliative care for children and young people** - this data was not available for this needs assessment, although numbers are small, this data would be useful for commissioners to use in order to ensure services are available to meet needs.
- Additional work would be useful to understand the numbers of children and young people that may be considered suitable for palliative care because the proportion of deaths that occur in hospital is relatively high, suggesting that there is a considerable challenge to improve access to palliative care services for children.
- **Equipment needs** - specialist equipment has not been addressed adequately within this needs assessment. It is recommended that a separate needs assessment be carried out looking at equipment for children and young people, pulling information together from a range of partners including NHS, Local Authority, Special Schools, parents/carers and children/young people. Projection planning would also be useful in terms of equipment needs.
- **Emotional health and well being needs** - the Health Needs Assessment for pupils in Special Schools identified that emotional health was not recorded as being a particular need in complex needs pupils. It is not clear if this is truly the case or because it is perceived that physical need is more important. It is recommended that the emotional health and wellbeing needs of pupils are explored in this group of children and young people as this figure is surprisingly low.
- **Qualitative feedback from professionals working with children and families** - to further assess unmet need it would be useful to engage a range of practitioners working in the field of Children's disability and SEN. They will help to discuss any barriers within pathways for children and their families, and will be able to identify gaps in service provision. Special School head teachers for example would be able to make a worthwhile contribution discussing a range of services and interventions.
- **Health Service Performance Data** - More comprehensive data should be collected from all local health services including those serving Bassetlaw. Data should include current performance levels to further assess needs.
- **Planned and unplanned admissions to hospital including A&E** - Anecdotally we know that disabled children are more likely to have unplanned hospital admissions including visits to accident and emergency departments. This needs assessment however could not confirm this anecdotal information. It is difficult to identify disabled children attending hospital from routine data due to the lack of a systematic way of identifying and recording this status, so there may be unmet need if data is not available.
- **Undertake 'access audits'** - it may be worthwhile to consider the development of an access audit of activities including, youth, play and leisure services to ensure that these universal services are inclusive and changes are made where required. It would also be useful to undertake health equity audits to ensure universal health services are also inclusive and engage disabled children and their families.
- **Housing** - identify local data on families with disabled children and the conditions in which they live (e.g. overcrowding, state of repair etc.)
- **Transport** - numbers of disabled children requiring transport, geographic spread, projections, analysis of costs - and barriers to participation created by a lack of transport provision.
- **Bullying** - there is no local data on disabled children and their experiences of bullying and hate crime.
- **Parents/Carers** - intelligence on the demands which local parents and carers (including young carers) of children with profound and multiple difficulties are under is very limited.
- **Obesity** - there is no local data on obesity and disability, as children unable to stand on scales are excluded from the National Child Measurement Programme. The National Child Measurement Programme does not ask to identify if children accessing the programme have a disability.
- **Immunisations** - nationally, children with physical or learning disabilities are identified as at risk of not being fully immunised. There is currently no local data available to monitor this
- **Kinship Carers** - no local data was available for this needs assessment that would help to identify the proportion of carers who are members of the family (excluding parents). Further work to understand and meet the needs of kinship carers in Nottinghamshire is required.
- **Workforce development needs** - evidence based practice recommends that a skilled workforce is needed in particular in universal services to ensure that they are inclusive. No data was available regarding how inclusive the local workforce is. It would be worthwhile therefore to assess workforce development needs.

## References

- <sup>1</sup> Department for Education (2011) Support and aspiration: A new approach to special educational needs and disability - a consultation' [www.education.gov.uk/publications/eOrderingDownload/Green-Paper-SEN.pdf](http://www.education.gov.uk/publications/eOrderingDownload/Green-Paper-SEN.pdf)
- <sup>2</sup> Sloper T (2004) 'Meeting the needs of Disabled Children' Quality Protects Research Briefings (no 6) Research in Practice
- <sup>3</sup> For the purposes of the DDA Act, references to disabilities that are substantial and long term means that the effect of the impairment has lasted or is likely to last for at least 12 months and affects normal day-to-day activities including everyday things like eating, washing, walking and going shopping. A normal day-to-day activity must affect one of the 'capacities' listed in the Act which include mobility, manual dexterity, speech, hearing, seeing and memory.
- <sup>4</sup> Department for Education and Skills (2006) 'Health and Well-being: Physical Health' Research and Practice Briefings: Children and Young People