

5 June 2013**Agenda Item: 11****REPORT OF THE CORPORATE DIRECTOR FOR CHILDREN, FAMILIES AND
CULTURAL SERVICES AND THE HEAD OF HEALTH PARTNERSHIPS****NEEDS ASSESSMENT FOR CHILDREN AND YOUNG PEOPLE WITH
DISABILITIES AND/OR SPECIAL EDUCATIONAL NEEDS IN
NOTTINGHAMSHIRE****Purpose of the Report**

1. To inform members of the Health and Wellbeing Board of the main findings of the needs assessment for children and young people with disabilities and/or Special Educational Needs (SEN) in Nottinghamshire, published in 2012.
2. To inform the Health and Wellbeing Board of work underway to develop integrated commissioning of services for children and young people with disability and/or SEN.
3. To inform the Health and Wellbeing Board of plans being developed to meet the proposed new duties for local partners to cooperate in the provision of health, education and social care, as detailed in the draft Children and Families Bill.
4. To sign up to the Disabled Children's Charter for Health and Wellbeing Boards.

Information and Advice**Background**

5. Children and young people with disabilities, long term health conditions and special education needs (SEN) experience poor health outcomes¹. This group of children and their families need services which are provided by multiple agencies, and therefore they are disproportionately affected by poor integration between services and by a lack of co-ordinated commissioning. Too often, they report frustration at fragmented services and the failure to deliver appropriate services at the right time. This leads to significant distress².

¹ Department of Health (DH) (2012) Report of the Children and Young People's Health Outcomes Forum
<http://www.dh.gov.uk/health/2012/07/cyp-report/>

² The Children's Trust (2012) Disabled Children and Health Reform
http://www.ncb.org.uk/media/428980/health_reform_report.pdf

National and Local Drivers

6. The new health system presents a unique opportunity to improve the quality of life experienced by children and young people with disabilities, long term health conditions and SEN, by improving the integration of the services they use.
7. In 2012 the Department for Education published '*Support and Aspiration: a new approach to SEN and disability - Progress and Next Steps*'. This guidance restated the Government's commitment that by 2014:
 - a new assessment process will be introduced leading to a single plan, the Education, Health and Social Care (EHC) Plan
 - the assessment process will cover children and young people aged 0-25 years
 - the process will include an offer of a personal budget for all families with an EHC plan as a means of offering more freedom of choice to families (detailed in the NHS Mandate)
 - a local offer will be in place, describing the support available to children and young people with SEND (special educational needs and disability), and their families
 - Local Authorities and Clinical Commissioning Groups (CCGs) will make arrangements to ensure that the needs of children and young people with disabilities and/or SEN are planned and commissioned jointly.
8. The Children and Families Bill has now passed its second reading in the House of Commons and committee scrutiny of the Bill began on 5 March 2013. During this process, it was announced that the Bill will be amended to place a legal duty on CCGs to secure health services that are specified in EHC Plans. This provides important clarity and reassurance to families in addition to the duties already in the Bill in relation to co-operation and joint commissioning³.
9. Every Disabled Child Matters (EDCM) and the Children's Trust, Tadworth, have created a *Disabled Children's Charter for Health and Wellbeing Boards* as a tool to support Health and Wellbeing Boards to feel confident that they are meeting their responsibilities towards children and young people with disabilities, long term health conditions and SEN. The Charter is attached as **Appendix 1**; benefits and local evidence to support signing of the Charter is attached as **Appendix 2**. The Integrated Commissioning Group for Children and Young People with Disability and SEN will develop a plan to ensure compliance with the Charter.
10. A survey of over 1,000 families with disabled children in England in 2012 found that 76% of families do not visit their GP about their child's disability or condition. For those that did visit they found the quality of care inconsistent⁴. Contact a Family has produced *GP*

³ Department for Education (2013) Indicative Draft: The (0-25) Special Educational Needs Code of Practice <http://media.education.gov.uk/assets/files/pdf/s/sen%20code%20of%20practice%20indicative%20draft%20for%20committee.pdf>

⁴ Contact a Family (2012) Putting families with disabled children at the heart of the NHS reforms in England

Practice guide: supporting disabled children and young people and *Making GP practices more welcoming for families with disabled children* which are practical guides for GPs, other health professionals and commissioners in making sure health services are accessible for families who have children and young people with disabilities.

11. Improving the effectiveness of services for disabled children through joint planning and commissioning is a priority in the Health and Wellbeing Strategy and the Children, Young People and Families Plan 2011-14.
12. In Nottinghamshire, the Integrated Commissioning Group (ICG) for Children and Young People with Disability and SEN has been established for two years and is a core group of the Nottinghamshire Children's Trust Board. The ICG includes representatives from Nottinghamshire County Council (Children and Adult Services, Public Health), Nottingham North and East (NNE) and Bassetlaw CCGs as well as parents and a representative from the Special Schools Federation. Commissioning of healthcare services for disabled children became the responsibility of CCGs on 1 April 2013.

Needs Assessment for Children and Young People with Disabilities and/or Special Educational Needs in Nottinghamshire

13. The Nottinghamshire Children's Trust Board undertook a needs assessment of children with disabilities and SEN in Nottinghamshire in 2011/12, with work overseen by the ICG. The needs assessment informed the development of an Integrated Commissioning Strategy. The Strategy aims to ensure that partner agencies work together, align resources and deliver their services effectively, providing value for money and improving the experience and outcomes for people using these services.
14. The executive summary of the needs assessment is attached as **Appendix 3**, together with key findings and recommendations.

Key Messages from the Needs Assessment

15. The key messages are as follows:
 - there are between 7,000 – 12,000 children and young people who experience some form of disability or long term condition in Nottinghamshire. The estimate is wide because different sources of information suggest different actual numbers when applied to the Nottinghamshire population. There is no one recognised reliable national or local source of data and definitions of disability vary widely. The Report of the Children and Young People's Health Outcome Forum in 2012 found one of the biggest barriers to improving outcomes for this group of children is a paucity of robust and comprehensive data
 - the prevalence of severe disability amongst children and young people is increasing as a result of improved survival of children and babies with complex needs. 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 in Nottinghamshire

- the number of children and young people with life limiting and life threatening conditions has doubled over the last decade
- there has been a 60% rise in young claimants (0-24 yrs) of Disability Living Allowance in Nottinghamshire over the last decade
- children who experience disability and SEN are more likely to live in poverty than the average. Nationally, 29% of disabled children live in poverty, compared with 21% of all children
- disabled children and young people have many of the universal needs of their non-disabled peers
- substantial inequalities persist between disabled children and young people and their peers in relation to fulfilling their health and educational potential
- for young people with disabilities or SEN, transition to adult services is often challenging
- locally, more children have choice and access to a wide range of short breaks and the number of children with disabilities accessing children's centres has increased
- the number of children and young people with disabilities receiving a direct payment has risen substantially since 2007/08
- over the last 10 years there has been a 72% increase in the number of accepted Universities and Colleges Admissions Service (UCAS) applications from disabled young people compared to a 16% rise in non-disabled peers
- there is a lack of data and performance information available on the services that disabled children and young people use
- consultation with local families in 2009 indicated that it is difficult to find out what services are available and that services on offer do not always help with the complex 'juggling act' required by families with a disabled child.

Why we need to do things differently: illustrative case studies

16. Below are brief summary notes from two case studies, one of a child with complex health, social care and education needs and one with additional but less complex needs. Families involved are keen to share this information in the hope that it can lead to improvements. The cases illustrate complexity in terms of interactions with services, highlighting that parents are not only parenting but are also carers, managers and coordinators of services. There is no description of the often significant impact this can have on marital and family life, economic activity and health and wellbeing of the wider family.

Case Studies

SEN and moderate health needs	SEND and complex care needs
<p>Emma* (born 1992) 13 years in education health & care</p> <p>Primarily neurological and developmental condition</p> <p>Used 6 statutory & 2 private services also 2 private funding sources for support to meet needs not met by statutory provision</p> <p>44 assessments completed and some of those are on-going</p> <p>19 Professionals involved</p> <p>10 organisations involved</p>	<p>Alice* (born 2003) 10 years health & social care support, 6 years in education (mainstream & special)</p> <p>Congenital, respiratory, neurological, ENT and orthopaedic conditions</p> <p>Used over 50 statutory services, 3 private services & 3 voluntary sector offering additional family support.</p> <p>Over 55 initial assessments. Completed. 34 services still active & assess/ review 6 monthly.</p> <p>Currently over 28 Professionals involved, this has varied over the years.</p> <p>55 organisations involved</p>

*names have been changed

17. In one single month Alice missed 12 school days through attending a variety of health, social care and education appointments. Her parent wanted to share the following thoughts:

"The services my daughter receives are generally excellent but when it comes to information, I do not know who holds what, where it is held and with whom it is shared."

"At times the volume of appointments and coordination of services can feel like a full time job."

"I often provide the same information to different services, which can be frustrating."

"I know about the services my daughter receives but I do not know what else might be available. Other parents are generally the best source of information for this."

"Professionals are often too busy to take on the role of key worker or lead professional which then places further pressure on parents to coordinate services."

"I should stress that the care received is good; it is the organisation that gets in the way!"

18. Emma's parent recorded part of her story:

"The most frustrating thing for me was that when she was around seven years old I knew something wasn't quite right for Emma and I knew it was associated with school. She was great during school holidays. I knew my child well: she has a strong character and was an intelligent articulate child capable of discussion, negotiation and reaching understanding and compromise. Over a period of time I noticed that she had become

impatient, easily frustrated and short tempered. She was, in plain language, unhappy but I couldn't find out from her what was troubling her. I spoke to her teacher at school about it on 3 occasions but felt fobbed off and not taken seriously. I later had the same experience with other teachers at Secondary School, the family GP and Practice Nurse. I am an intelligent, well educated professional, used to being listened to but found myself in a position where I was not been treated seriously and what I had to say was meaningless. I learned almost immediately that I had to fight to be listened to and heard. I became a warrior parent and Emma has learned to do the same and we haven't stopped fighting yet.'

19. Consultation has indicated that parents and carers are generally happy with services once they receive them, rating them very good or excellent. It is the process of accessing, the coordination and management that are not satisfactory.
20. Both young people and parents consulted as part of the needs assessment highlighted the need to improve the access to and coordination of services and the sharing of information.

Why children are different

21. Children generally have little direct control over factors that can affect their health, or the wide range of determinants of health. A child's problems may be a symptom of family dysfunction and so providing effective support for parents and families can have a profound impact on the health and well-being of their children. Thus, those planning and commissioning children's services must also consider the services provided to parents, particularly where parental factors, such as learning difficulties, mental health problems, substance abuse or experience of domestic violence, can have an adverse impact on their children.
22. For children, accessing the services they need can be more complex than for adults, largely as a result of their dependence on their family or carers. In addition, children's services are fragmented, smaller and geographic access may be more problematic.

The Nottinghamshire Response

23. The Children and Young People's Disability and SEN Integrated Commissioning Group identified the following priorities from the needs assessment:
 - develop robust, accurate information systems to enable commissioners to more effectively commission services to meet the needs of the local population
 - ensure co-ordinated planning at all levels, with roles and responsibilities of different agencies clarified and understood by frontline staff working with children, young people and their families
 - increase joint commissioning to reduce silo working across agencies working with the same children and families

- increase integration and joint delivery of services, to ensure that there is a consistent approach, reduced duplication, improved efficiencies and clearer pathways for children, young people and families
- use evidence based practice to shape local services and interventions, and help build the evidence base through robust evaluation of interventions and processes.

How these priorities are to be met through the Integrated Commissioning Strategy

24. Work on a number of areas is underway to improve services for disabled children, with two specific priorities identified for focused work because of their potential impact and the forthcoming legislation, namely:
 - to implement Nottinghamshire's SEN and Disability (SEND) Pathfinder, known locally as the 'One Project', testing approaches to a single assessment and planning process. From September 2014 this process and the single Education, Health and Social Care (EHC) Plan will replace the statutory Statements of Special Education Needs (for under 16s) and Section 139a Learning Difficulty Assessments (for over 16s). The Pathfinder programme summary is attached as **Appendix 4** and the proposed integrated model as **Appendix 5**
 - to undertake the Integrated Community Children and Young People's Healthcare Programme (ICCYPH) which brings together providers of services, families, NHS Nottingham City CCG, NNE CCG, Nottinghamshire County Council (including Public Health) and Bassetlaw CCG to work together to improve access to and co-ordination of community healthcare services for children and young people. The programme summary and brief are attached as **Appendices 6 and 7** respectively.

SEND Pathfinder

25. The Nottinghamshire SEND Pathfinder (the 'One Project'), is one of 20 Pathfinders making up the Government's national SEND Pathfinder Programme and has been extended for 18 months, until September 2014. During this extension phase, the 20 Pathfinders will continue to test the planned reforms detailed in paragraph 6 of this report, to inform the Children and Families Bill, which contains the new SEN legislation and new SEN Code of Practice, as it progresses through Parliament.
26. Whilst it is expected that the new legislation will not be implemented in England until September 2014, a condition on all the Pathfinders is that they will introduce their new arrangements in advance of this date. In Nottinghamshire it is intended that there will be a phased roll-out starting from 1 September 2013 with arrangements fully operational by 1 January 2014.
27. A Pathfinder Project Board and Project Team have been established and will lead the changes required to deliver the new systems and processes, working with colleagues from education, health and social care services and with children, young people and their families.
28. To date 21 families have been recruited to the Nottinghamshire 'One Project' Pathfinder, with each involved in testing different elements of the new assessment and single plan

process, this is set to increase during the Pathfinder extension phase. A small number of these families are taking on personal budgets to help deliver the outcomes identified in their plan.

29. A key feature of the new assessment and single planning process is that, unlike the current process for Statements of Special Educational Needs (for under 16s) and Learning Difficulty Assessments (for over 16s), families and young people are able to express their views at an early stage, through the completion of an 'All About Me' personal profile. This profile looks at the whole day, not just the school day, and has a positive emphasis rather than offering a deficit model focused on what the child or young person is not able to do.
30. A number of other families not directly recruited to the Pathfinder are also involved, for example, in helping to shape the development of the local offer that will describe the support available.

The Integrated Community Children and Young People's Healthcare (ICCYPH) Programme

31. The vision of the programme is to enable children and young people with acute and additional health needs, including disability and complex needs, to have their needs met wherever they are. Services will support the child's life choices rather than restrict them and will improve the quality of life for children and their families and carers. The aim of the programme is to develop a Nottinghamshire wide integrated model of children's healthcare, delivered via a network of community based services.
32. Scoping has been undertaken to identify local and national developments which may influence the outcomes of the programme. Consultation with children, families and professionals together with population and service data collection and analysis is underway.
33. Following completion of the above work, recommendations will be published, in relation to future commissioning of community health services for children and young people in Nottinghamshire County and Nottingham City.
34. The two areas of work detailed above require effective multi-agency work and there is considerable overlap between the projects. It is recommended that for children and young people with disability and SEN, the two work streams now integrate.

Integrated commissioning of services for children and young people with disability and SEN

35. In April 2013, the Nottinghamshire Children's Trust Board and the Health and Wellbeing Board approved the development of an Integrated Commissioning Hub, which will discharge commissioning responsibilities on behalf of CCGs to Nottinghamshire County Council for a range of children's health services. The function will include commissioning of services for children and young people with disabilities and SEN. Governance will be through the Nottinghamshire Children's Trust Board to the Health and Wellbeing Board and to Nottinghamshire CCGs. This will facilitate integrated planning, commissioning and

provision of services, to meet the health and well-being needs and improve outcomes for children and young people.

Other Options Considered

36. None.

Reason/s for Recommendation/s

37. The needs assessment has highlighted a number of recommendations that are being taken forward through the Integrated Commissioning Group for Children and Young People with Disability and SEN. As improving the effectiveness of services for disabled children through joint planning and commissioning is a priority in the Health and Wellbeing Strategy and the Children, Young People and Families Plan 2011-14, it is important the Health and Wellbeing Board are given the opportunity to review and comment on the progress of this work.

Statutory and Policy Implications

38. This report has been compiled after consideration of implications in respect of finance, the public sector equality duty, human resources, crime and disorder, human rights, the safeguarding of children, sustainability and the environment and those using the service and where such implications are material they are described below. Appropriate consultation has been undertaken and advice sought on these issues as required.

Equalities Implications

39. Due regard has been given to the Public Sector Equality Duty.

RECOMMENDATION/S

That the Health and Wellbeing Board:

- 1) is invited to comment on the current approach to improving health and wellbeing of children and young people with disabilities and/or special educational needs (SEN), as detailed in this report.
- 2) notes the on-going work in both the SEND Pathfinder and the Integrated Community Children and Young People's Healthcare (ICCYPH) Programme to move to an integrated model of commissioning and delivery for children and young people with disabilities and/or special educational needs.
- 3) signs up to the *Disabled Children's Charter for Health and Wellbeing Boards*.
- 4) receives an update on this area of work when the Children and Families Bill is published in 2014.

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Constitutional Comments (KK 24/05/13)

40. The proposals in this report are within the remit of the Health and Wellbeing Board.

Financial Comments (NDR 24/05/13)

41. There are no financial implications arising directly from this report.

Background Papers and Published Documents

NCC (2012) Web link for the Integrated Commissioning Group (ICG) for Children & Young People with Disability and SEN: Needs Assessment, Strategy and Terms of Reference.
www.nottinghamshire.gov.uk/improvetheeffectivenessofservicesfordisabledchildren

Department for Education (2012) Support and Aspiration: A new approach to special educational needs and disability

DH (2012) The Mandate: A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/127193/mandate.pdf.pdf

Contact a Family (2013) GP practice guide: supporting disabled children and young people
Contact a family (2013) Making GP practices more welcoming
NCC (2012) Our Strategy for Health and Wellbeing in Nottinghamshire
NCC (2011) Nottinghamshire Children, Young People and Families Plan 2012-13 update

NCC (2011) The Early Intervention and Prevention Strategy
<http://www.nottinghamshire.gov.uk/caring/childrenstrust/pathway-to-provision/earlyinterventionpreventionstrategy/>

NCC (2012) The Pathway to Provision Multi-agency Thresholds Guidance
<http://www.nottinghamshire.gov.uk/caring/childrenstrust/pathway-to-provision/>

Except for previously published documents, which will be available elsewhere, the documents listed here will be available for inspection in accordance with Section 100D of the Local Government Act 1972.

Electoral Division(s) and Member(s) Affected

All.

C0227