


MEETING DATE:	12 July 2012	 North Lincolnshire Clinical Commissioning Group REPORT TO THE CLINICAL COMMISSIONING GROUP COMMITTEE
AGENDA ITEM NUMBER:	Item 6.2	
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JOB TITLE:	Acting Head of CYP and Maternity	
DEPARTMENT:	Commissioning	

**MEETING THE HEALTH CARE NEEDS OF DISABLED CHILDREN AND YOUNG PEOPLE IN
NORTH LINCOLNSHIRE: CQC REPORT MARCH 2012**

PURPOSE/ACTION REQUIRED:	To Receive & Note
CONSULTATION AND/OR INVOLVEMENT PROCESS:	Not applicable
FREEDOM OF INFORMATION:	Public

1. PURPOSE OF THE REPORT:	
<p>In 2011 the Care Quality Commission (CQC) undertook a national special review of how the health care needs of disabled children and young people are met by commissioners and providers of healthcare and other services the report was published in March 2012.</p> <p>The purpose of this report is to provide an overview of the findings of the review to the NHS North Lincolnshire Clinical Commissioning Group Committee (CCGC). This will include:</p> <ul style="list-style-type: none"> • Background to the review • The overall findings of the review within a national and local context • The relation of the report and its findings to the CCG Commissioning Strategy 	
2. STRATEGIC OBJECTIVES SUPPORTED BY THIS REPORT: <i>(will be populated following agreement with Council of Members)</i>	

3. IMPACT ON RISK ASSURANCE FRAMEWORK:	<table border="1"> <tr> <td>Yes</td> <td></td> <td>No</td> <td>x</td> </tr> </table>	Yes		No	x
Yes		No	x		
4. IMPACT ON THE ENVIRONMENT – SUSTAINABILITY:	<table border="1"> <tr> <td>Yes</td> <td></td> <td>No</td> <td>x</td> </tr> </table>	Yes		No	x
Yes		No	x		
5. LEGAL IMPLICATIONS:	<table border="1"> <tr> <td>Yes</td> <td></td> <td>No</td> <td>x</td> </tr> </table>	Yes		No	x
Yes		No	x		
6. RESOURCE IMPLICATIONS:	<table border="1"> <tr> <td>Yes</td> <td></td> <td>No</td> <td>x</td> </tr> </table>	Yes		No	x
Yes		No	x		
7. EQUALITY IMPACT ASSESSMENT:	<table border="1"> <tr> <td>Yes</td> <td></td> <td>No</td> <td>x</td> </tr> </table>	Yes		No	x
Yes		No	x		
8. PROPOSED PUBLIC & PATIENT INVOLVEMENT AND COMMUNICATIONS:	<table border="1"> <tr> <td>Yes</td> <td>x</td> <td>No</td> <td></td> </tr> </table>	Yes	x	No	
Yes	x	No			
<p>Disabled Children and Young People are a key local priority and the CCG works in close partnership with North Lincolnshire Council in commissioning a range of services for this client group. Public and Patient involvement will be sought through the Parents in Partnership PIP forum. This report will be shared across the local partnership.</p>					
9. RECOMMENDATIONS:					
<p>The CCG is asked to: -</p> <ul style="list-style-type: none"> • Receive the report; • Consider the issues raised, the recommendations and any further actions required; • Agree to the distribution of this report across local partners; • Request updates to be presented to the CCG Engine Room re progress. 					

**A review of how the health care needs of disabled children and young people
are met by the Commissioners and providers of health care in England.
(Care Quality Commission March 2012)**

1. Introduction

This report provides an overview of the findings of the Care Quality Commission (CQC) national special review of how the health care needs of disabled children and young people are met by commissioners, providers of healthcare and other services. National and local reports for all PCTs were published in March 2012.

2. Background

In 2011 the CQC concluded a special review of services for disabled children and young people. It was a mandatory data collection process via a questionnaire to the PCT covering the period **30th September 2009 to 30th September 2010**. Data was collected from all PCTs and relevant acute trusts between 7 January and 14 February 2011 and all organisations had the opportunity to ratify their submitted data from 18 May to 8 June 2011. It should be noted that due to the time lag in publishing the report the data/information submitted is now out of date.

The overall information collected revealed a complex and variable picture of how services are commissioned and provided to children and young people with a disability, and their families and carers.

The review looked at the support available for families with children that have a disability and focused on families that have children under the age of 19 with:

- a learning disability
- autism or Autistic Spectrum Disorders
- communication needs
- sensory needs
- mental health and behavioural support
- mobility needs
- technology dependence

In particular, this review looked at:

- availability of specialist health services for disabled children and young people and their families.
- assessment of the quality of support in a geographical area linked to primary care trusts (PCTs).
- 'building blocks' of the care pathway that are of particular importance to families.

The methodology included:

- a series of interviews, group sessions and questionnaires with about 82 individuals from the 'SpeakOut' groups (a network of community groups supported by the CQC and the University of Central Lancashire),
- meetings with stakeholders to establish what the review would ask commissioners, and
- provider focus group meetings to explore the issues raised by the analysis of the data.

The national report and local reports for all other PCTs can be found on the CQC website.

<http://www.cqc.org.uk/public/reports-surveys-and-reviews/reviews-and-studies/support-families-disabled-children>

3. Findings of the review

The review presents the views and experiences of disabled children and their families as well as survey data from commissioners and acute hospitals about services provided from September 2009 to September 2010. It should be noted nationally and locally there was often significant disparity between the experiences of disabled children and their families, which were overwhelmingly negative compared to the data supplied by primary care trusts, which showed high levels of access and user-centred care.

Findings included:

- families felt access to and involvement in services was a challenge and that they waited too long for access to services and for initial diagnosis.
- contributors felt services were not joined up and that different services did not work well together.
- many disabled children and their families also reported they had not been consulted on how their care had been provided.

The SpeakOut groups and other stakeholders reported negative experiences particularly around how well services were joined up, how well they were involved in decisions, the delivery of care, communication and general quality of care being provided. They also expressed frustration and felt they had to be persistent in getting the services they needed. Service users provided a list of indicators of what they felt 'made a good service'. These could be applied as practical steps to improve services.

Information collected from PCTs to some extent supported the service user reported experiences, confirming that people using services have a range of different experiences. There was variation in the use of Health Action Plans, coordination

between services and waiting times for services. This variability may in some way explain why service users/stakeholders generally reported poor experiences of their care and support. Generically there was a low level of complaints. There was a difference between the PCT reported information and service user experience with PCTs generally reporting a 'positive picture' that was not reflected in the experiences of children and families. Some PCTs were unable to provide all of the information required.

The review also looked at key documents released during the period of the review. It was found that these reflected the findings of the review and validated the data collected, adding to the information and debate about what needs to be tackled to provide better services to families with a disabled child or young person.

Section 3.1 gives further details in relation to service provision in North Lincolnshire and in comparison to other PCT responses.

3.1 Snap Shot of Local Service provision

A local report has been published for all PCTs this is a summary of NHS North Lincolnshire response.

North Lincolnshire PCT named the following organisations as providers of its commissioned services:

- JCCM
- Elite Care Solutions
- NHS North Lincolnshire Community Services
- Northern Lincolnshire and Goole Hospitals NHS Foundation Trust
- Sunshine House
- St Andrews Hospice
- Bluebell Wood Children's Hospice

Health Action Plans (HAP) describe what young people can expect from their care as well as advice on how to stay healthy.

- NHS North Lincolnshire reported that 50-80% CYP have a HAP which was developed with the young person.
- Other PCT responses varied with the majority (29%) reporting some (20 – 50%) and 24% of PCTs reported most (over 80%) having a HAP.

Joined up services describe specialist services that should be well coordinated with other services, providing the best experience for service users and enhancing capacity.

- The majority of PCTs, including NHS North Lincolnshire, reported that therapy services were coordinated in relation to shared appointments, and that over 80% of assessments were shared with allied professionals, professionals from other services and families. In addition, arrangements are in place through which community providers share information with acute services to support planned admission and share information in an emergency about individual children/young people's needs. Acute services involve community staff in discharge planning.

Involvement

It was reported that disabled children and their families were sometimes involved in interviews or the assessment process but they were involved nearly always in induction and/or training of staff who deliver their care packages

Access to services (between the period 1st April and 30th September 2010)

- *Speech and Language Therapy*
NHS Lincolnshire reported an average wait of 8.53 weeks.
(updated position = the 10 week target remains in situ but typically children are seen within 6-8 weeks for their first appointment. Children who require a more urgent response (eg feeding difficulties) will be seen within days of the referral being received).

The national average wait was 12 weeks and waiting times ranged from 0 – 311 weeks.

- *Community Physiotherapy*
NHS North Lincolnshire report this average wait was 3 weeks.
(updated position = the service continues to deliver against the target of a maximum 4 week wait for all children).

The national average wait was 7 weeks and waiting times ranged from 0 – 30 weeks.

- *Community Occupational Therapy*
NHS North Lincolnshire reported 16.8 weeks
(updated position = children who are prioritised with greater clinical need will be seen within 12 weeks; children who have less urgent needs (typically those referred for motor coordination difficulties) are seen within 18-20 weeks.

The national average wait was 14 weeks and waiting times ranged from 0 – 94 weeks.

- *Short Breaks*
5 children and young people were referred for a short break during this period.

- *Wheelchairs, aids and equipment*

Locally, the waits between receipt of referral to the service and receipt of their wheelchair or special seating was 1 week for a lightweight manual chair, 35 weeks for a powered chair.

(updated position = once the child has been assessed, the typical wait to issue a chair is 6-8 weeks – this is because the majority of children require a new chair and this has to be ordered and supplied by the various manufacturers. If a suitable chair is already in stock, this can be issued the same or next day.)

The national wait for a lightweight manual chair was 8 weeks and waiting times ranged from 0 – 59 weeks. The national average wait for a powered chair was 10 weeks and waiting time ranged from 0 – 77 weeks.

- *Communication aids*

In terms of communication aids, it is worth noting that NL has a multi-agency system for considering the provision of this equipment and includes health, education and social care. This means that children are assessed through a single process (which looks at their needs for a communication aid in all settings) and then funding recommendations are addressed through the relevant partners working together. This model has had national recognition.

3.2 Recommendations of the Review for NHS North Lincolnshire CCG

NHS North Lincolnshire

- Work is still required to improve services in relation to wheel chair provision and OT. Work has progressed in relation to CYP and parental engagement. An annual review of services for disabled children and young people, covering standards, access, coordination and continuity of care should be undertaken.

NLaG will be undertaking work as part of the national HiTAP programme to look at the potential initiative “Child in a Chair in a Day” – this initiative seeks to reduce the time delay in providing children with a wheelchair, drawing on the model developed by WhizzKids.

- Improve the quality of information from providers of services for disabled children.

3.3 Context of the report and its findings in relation to the CCG Commissioning Strategy

There have been changes in the commissioning and provision of services since the collation of the data including a revised services specification for an Integrated Paediatric Therapy Service, therefore, some of the findings of the review may no longer be current. A Children's Therapy Team came into effect in May 2012 and was the result of extensive consultation. Parents of disabled children were asked for their views. Feedback was that a multi-disciplinary team would provide the structure to underpin the integrated working which already takes place between individual practitioners and families.

There has also been a significant culture change in involving CYP/parents/carers in the assessment process mainly in relation to the new continuing care process.

The general findings of the report should however be taken into account by NHS North Lincolnshire CCG and partners in the commissioning, planning, delivery and evaluation of local services for disabled children, young people and their families.

Service user experience is a key performance measure in all newly developed service specifications. Engagement and feedback on the commissioning (planning, development, delivery and evaluation) of services for disabled children is sought on a regular basis through the local Parents In Partnership (PIP) forum. A range of measures will be explored to ensure CYP and their families are heard, their views acted upon and relevant actions recorded.

4. Recommendations

The CCGC are asked to:

- Receive the report;
- Consider the issues raised, the recommendations any further actions required;
- Agree to the distribution of this report across local partners; and
- Request updates to be presented to the CCG Engine Room re progress.