

Patient Story

Subject:	Special Educational Needs and Disability (SEND) Service
Summary:	Patient feedback on the newly implemented approach to Special Educational Needs and Disability services including the commissioning of a new, integrated community health service for children and young people with additional needs and disabilities, now known as Community Children and Young People's Service (CCYPS).

1. Introduction

Bringing patients' or their carers' stories/ experiences into the Board is welcomed by the Governing Bodies as a mechanism for understanding the impact of the services we commission, positive and negative, on service users. Patient Stories are advocated as a powerful catalyst for change by the Institute for Healthcare Improvement (www.ihl.org).

Patient stories are a key feature of our ambition to revolutionise patient experience. They provide a focus on how, through listening and learning from the patient voice, we can continually improve the quality of services and transform patient and carer experience.

2. Background and Context

The vision for children with special educational needs and disabilities is the same as for all children and young people – that they achieve well in their early years, at school and in college, and lead happy and fulfilled lives. We know that healthy, happy children perform well at school, and we know how significant an impact a child's health has on their life chances.

The Special Educational Needs and Disability (SEND) reforms outlined in the Children and Families Act 2014 are focused on outcomes for children and young people (CYP) with SEND and how education, health and social care work together to help CYP aged 0-25 achieve their outcomes. For too long, health has been the missing partner in the SEND system, although within Nottinghamshire there has always been proactive engagement with health colleagues and education. Nationally, the reforms embed this – they implement a holistic approach to supporting children and young people with SEND in all aspects of their life.

For children and young people this means that their experiences will be of a system which is less confrontational and more efficient. Their special educational needs and disabilities will be picked up at the earliest point with support routinely put in place quickly, and their parents will know what services they can reasonably expect to be provided. Children and young people and their parents or carers will be fully involved in decisions about their support and what they want to achieve. Importantly, the aspirations for children and young people will be raised through an increased focus on life outcomes, including employment and greater independence.

The reforms include a move from children having a 'statement' of special educational need and disability to having an integrated education, health and care plan (EHCP) which has been developed in partnership with the child, their family and relevant leads from health, education and social care. This integrated working across sectors leads to better commissioning of services with a more transparent and efficient process of assessment and planning. It removes duplication of effort, by bringing different commissioners together at an

early stage, pools or aligns resources, and involves children, their families and carers in decision making about services they receive. Transfers from a statement of education to an ECHP need to be complete by March 2018. From May 2016 a new joint local area inspection programme undertaken by the Care Quality Commission (CQC) and Ofsted commenced. Over the first 5 years these inspections are narrative only to assess how well the reforms are being implemented within the local area.

Nottinghamshire

The Nottinghamshire Childrens Integrated Commissioning Hub (NCICH) was established in late 2012, this was to bring together commissioning for children and young people's health care services on behalf of the Nottinghamshire Clinical Commissioning Groups, (CCGs) and Public Health, Nottinghamshire County Council (NCC).

The NCICH vision is to be regarded as leaders in commissioning cost effective health and wellbeing services for the children, young people and families of Nottinghamshire; investing in them so that they have the best start in life and build healthier and resilient communities.

A joint programme, the Integrated Community Children and Young People's Healthcare programme (ICCYPH), now known as Community Children and Young People's Service (CCYPS) between the 5 Nottinghamshire County CCGs and Nottingham City CCG was established to develop a new, integrated community health service for children and young people with additional needs and disabilities.

The new community services contract was implemented from April 2016. The NCICH provides co-ordination and a single point of accountability for children and young people's health and wellbeing related commissioning.

The aim of this service is to streamline the complexity that exists around the planning of countywide children's health services. The integrated service includes Physiotherapy, Speech and Language Therapy (SALT), Occupational Therapy, Special School and Community Nursing, including End of Life Care and Phlebotomy. The new service involves multi-disciplinary staff working in integrated locality teams. All records are now kept on one single system and a Single Point of Access (SPA) has been established. The aim of this integrated system is to provide a seamless service to children and their families. Since the new service was implemented waiting times have been improved.

Within the first year of the contract, following in-depth consultations with children and their families and with the involvement of the Nottinghamshire Partnership Hub, the services were redesigned. The transformation programme was co-produced with families including development of the "Families Statement of Expectations", which underpin the services – the 10 points highlight the commitment to the values and principles which children and families identified as important to them.

Families Statement of Expectations (As part of the ICCYPH/CCYPS)

Our values are...

- Respect
- Collaboration
- Continual improvement

1. "No decision about me without me".

We are consulted and listened to, heard and treated with respect as experts on our/our own child's condition and have our views taken into account at all times.

2. Access to information and supplies.

We can easily get information, advice and guidance, and the services and supplies that we need, when we need them, so that our family can enjoy the best possible health and fulfilling lives. This should enable and support our roles, lifestyle choices and aspirations.

3. Whole systems working.

There is collaborative, joined up and timely planning and service delivery, with all parts working as a whole across all organisations and agencies involved in every aspect of our children's care.

4. Child/young person centred care.

Every child/young person is treated as an individual.

5. Communication and record sharing.

There is timely communication and shared documentation including core essential information about our children, their condition and their support between all those who need to be involved.

6. Capacity, competency and empathy.

We are confident that there are enough staff, who have the right knowledge, skills and expertise for what they are there to do, and they demonstrate this by empathy and understanding in all contacts.

7. Transition.

Children/young people are supported to achieve responsibility for themselves as adults and the family is supported during this period of transition to adulthood and reduced dependence on the family.

8. Continual improvement.

We can see that everyone involved in our children's care is committed to continually improving what they do.

9. Care environment.

Children/young people are seen in age appropriate environments furnished and equipped to meet their needs, taking into account chronological and developmental age.

10. Safety.

At all times our children are protected from harm.

A comprehensive quality outcomes framework, aligned to the priorities identified by families in their 'Statement of Expectations' underpins the transformation programme. To incentivise delivery against the outcomes, a local CQUIN (Commissioning for Quality and Innovation) has been developed and a process for evidencing progress against the framework to achieve incentive payments has been agreed. These priorities include reduction in

avoidance of hospital admissions, patient satisfaction with service and timeliness of assessment and treatment. Quality visits are also undertaken as part of the monitoring process.

4. Inspection – Care Quality Commission & Ofsted

Nottinghamshire Local Area was one of 20 Pathfinders to implement the SEND reforms prior to the legislation change in September 2014. The success of the pathfinder was augmented by co-location of the NCICH within the local authority, and health, education and care colleagues working together. In June 2016 Ofsted and the Care Quality Commission carried out one of the first joint inspections in Nottinghamshire County to judge the effectiveness of the area in implementing the reforms.

The main findings of the inspection identified:

- Children and young people describe very positive experiences of the support they receive from health services, social care provision and their education setting.
- Inspectors found a high level of commitment to implementing the reforms from all stakeholders. Approaches such as the education, health and care hub meetings are promoting the improved identification of children and a young person's needs and also improving their outcomes.
- The local area's evaluation about how well it has implemented the reforms is broadly accurate. However, the local area's self-evaluation does not include sufficient reference to the views of parents, children and young people.
- Most parents who spoke with or contacted the inspectors during the inspection had some dissatisfaction with at least a part of the access to health provision, social care services or education. The level of dissatisfaction was a concern to the inspection team and leaders from the local area, including the corporate director of children, families and cultural services. However, inspection evidence indicates that parental dissatisfaction is often successfully resolved when it is identified. Special educational needs appeals by parents across Nottinghamshire are at a lower rate than found nationally.
- Health visitors and school nurses are effective in identifying children's needs at an early opportunity and this helps them to put effective support in place to improve their outcomes.
- National comparative information indicates that fewer children and young people in Nottinghamshire are identified as having special educational needs and/or disabilities than found in other areas nationally. Significantly fewer children and young people than found nationally have an education, health and care plan. Children and young people tend to have their needs met quickly because families of schools are able to draw on expertise and funding from within their family of schools group.

The following are findings that had particular relevance to health:

- The 'tell it once' approach to identifying children and young people's needs is not well embedded. Although the use of a single electronic system aids health professionals' ability to see the information from some other teams, there are delays in

communication between colleagues, particularly between acute and community services. A pilot project in one locality has reduced the number of times parents have had to tell their stories to different services. The project has improved the efficiency with which services are provided to children. *(The pilot has since been rolled out).*

- The new integrated community, children and young people's healthcare service is not yet working as well as it could. This is particularly in relation to the provision of therapy services, such as speech and language therapy and occupational therapy. *(It should be noted that at the time of the inspection the new services had been running for less than three months).*
- Health teams do not always use effective outcome measurement tools (the means by which they are expected to assess how well they are doing). Plans are not sufficiently focused on health outcomes. *(The new service contract includes a quality outcome framework including use of the East Kent Outcomes System for monitoring outcomes for children and young people with SEND).*

A parent of a 13 year old boy who attends a school within the county which caters for children with special educational needs took part in the survey which formed part of the report.

"I would agree with the issues that have been raised in the report by inspectors. To be honest the outcome is what I expected because there are challenges accessing support. I would have thought that the council now has to take note and hopefully there will be changes. In our experience the quality of provision our son receives is of a very high standard, but access is an issue."

Local Authority and Health Commissioners acknowledged that there was more to do to support young people with special educational needs and disability, in particular, in their transition to adulthood. The multi-agency plan developed in response to the SEND reforms and updated in light of the inspection findings sets a clear direction for improvement and all partners are working hard to deliver this.

5. Patient Feedback for the newly implemented ICCYPH/CCYPS

At the time of the joint CQC/Ofsted inspection in June 2016 the new CCYPS service had only been in operation from 1 April 2016. The service reviewed the findings of the inspection and has continued to ensure that these inform their ongoing transformation plan. There are positive improvements in families experience being evidenced through the routine data collection and monitoring of quality outcomes framework for the service. Some notable achievements are:

- The number of complaints has reduced (none have been received since October 2016);
- 100% of families are satisfied with their electronic care plan, are involved in setting their own outcomes and report their history and care plan are well known by those involved in their care;
- 90% of families agreed that they have control over their own care and are involved in decisions about them.
- Examples of good practice – the respiratory service is working well to keep children out of hospital and well.

Compliments on the service are increasing. The following provides some examples of the compliments received:

Compliments for Paediatric Services

Speech & Language Therapies

'Communication was great all the way through – fabulous team'

'The session was tailored to xxx needs, xxx was made to feel at ease. Everything was explained and we were given choices on the next steps. SLT was very friendly and obviously confident in her role, which put everyone at ease'

Physiotherapy

'The staff were great at not placing limitations on us just because of diagnosis or condition, always trying to find ways of making things possible. Very positive team super helpful with physio and checking / sourcing equipment. Brilliant links with Nursery'

Community Nursing

'Great availability to fit in with schedules. Wonderful, friendly, helpful, caring staff. Provide a valuable service, saving hours of waiting in hospital. Made me feel safe even in my own environment. Friendly and happy'

'Good appointments system once being seen. Excellent communication between parent and Speech and Language therapy'

Information provision:

'Thank you so much for the information you have provided. I now feel like I have a starting point!' (parent Mid Notts seeking nursery place for child with additional needs)

'The information sent was really, really useful, there were lots of things he (child with disabilities) could do'

Feedback comments on Drop In sessions

'With regards to the meeting sessions I find them very useful, I think the sensory sessions are good and also the anxiety related ones, eating & sleeping sessions as I feel this affects nearly every parent & child.'

Areas of continuing concern have been identified as:

- The experience for families involved in Continuing Healthcare (CHC) falls short of the standards the service would like. The team are working with local authority partners to meet these expectations.
- Services for children with autism, SALT wait times are too long.

Actions underway to address these concerns include:

- Review to be undertaken on how we meet the needs of the most complex children in coordination with local authority partners and following engagement with children/ young people/ parents and families.
- SALT provision particularly for children with autism.
- Strengthening support during transition to adulthood.
- A review of the concerning behaviour pathway.

Feedback from the CCYPS team,

“Things have improved, but there’s lots more to do”.

6. Action Taken By Commissioners and Triangulation of data

The table below shows the work undertaken by the NCICH on behalf of the CCGs to ensure that they meet their statutory duties in the Children and Families Act 2014. In May 2016 the Nottinghamshire County and City CCGs funded a permanent Designated Clinical Officer (DCO) post working within the hub to ensure that the CCGs continue to meet these statutory duties-this was following a successful pilot of the DCO role from February 2015 funded by the SEND implementation grant. An Associate DCO post also joined the team in September 2016.

Statutory Duties for CCGs	Work undertaken by the DCO and ICH
Commission services jointly for 0-25 year old CYP with SEND, including those with Education, Health and Care Plans (EHCP)	<p>There has been a significant increase in requests (28.2%) for an EHCP. This appears to correlate with the CQC OFSTED inspection letter being published in August 2016 and the subsequent higher profile of the process.</p> <p>Community Children and Young Peoples Service (CCYPS) is now 12 months into the implementation plan. Progress is on track and positive impacts are being felt. Future plans are for clinicians from CCYPS to attend the EHCP decision making panel.</p> <p>The fortnightly multi agency panel for CHC for CYP is fully established. As a result, decisions are being taken fairly, with due regard to the need for financial efficacy. There is currently some challenge from the special schools with relation to funding within schools and a proposal for a new way to support children with continuing care needs within schools is being considered.</p> <p>Joint resolution and mediation process being developed between CCGs and the LA, to dovetail in with the EHCP process and Continuing Healthcare-which will also align across City/County (mid and South Notts CCGs).</p>
Ensure that procedures are in place to agree a plan of action to secure provision which meets	<p>The DCO and Associate DCO remain on the weekly panel for EHCPs, to ensure an appropriate decision is taken with regards to a health need.</p> <p>As a result of the CQC OFSTED Local Area inspection held last</p>

CYP 'reasonable' health needs in EVERY case	year, a health work stream has been established within the Newly formed SEND Accountability Board-one of the key priorities is to improve the "health" content of the Statutory document of the EHCP. The CCGs are working with the NCICH to consider how services for children with additional needs and disabilities may be delivered in most cost effectively in 2017/18 and beyond. Views of children/ young people, parents, families and clinicians will be taken into account in the commissioning of future services.
Work with the LA to contribute to the local offer	This is now part of new provider contracts - the expectation is that the provider maintains their service updates. Further work is being undertaken by the Associate DCO with health providers to ensure that this remains current.
Ensure mechanisms are in place to ensure practitioners and clinicians will support the integrated education health and care assessment within 20 weeks.	All CYP community service specifications include this and is an indicator in performance monitoring. This also includes adult community services specification which cover transitions and up to age 25 where appropriate. Further work to streamline this process is being undertaken by the DCO team. However additional demand in requests for EHCPs has impacted on the quality of some assessments.

The CCG Quality Team and representatives from the NCICH undertook a quality visit as part of the CCYPS contract monitoring in December 2016, eight months after the new service was implemented and eight months into a two year transformation plan.

Commissioners, Quality and Provider leads agreed that as a result of 'areas for improvement' outlined in the June 2016 CQC/OFSTED local area inspection this quality visit would focus on therapies and in particular speech and language and occupational therapy.

Reviewing the specific areas that were mentioned in the CQC/OFSTED inspection, Commissioners wished to understand families' experience of the provision, practitioners' views on the new service and their views on the use of the East Kent Outcomes System (EKOS) for monitoring outcomes for children and young people with SEND.

The visit provided positive assurance with the following noted:

- Friends and Family Test (FFT) results of 97%
- User service quality rating of 96%
- Families reporting seamless transition to the new service
- Use of outcome measures including EKOS
- 7 complaints and 5 compliments received in the previous 6 months, all relating to SALT
- The length of time between assessment and establishing packages of care had reduced with SALT therapists having their own nominated caseloads
- Staff reported that having access to SystemOne and mobile working was going well
- Staff also reported that although there had been some communication issues/ stress in the early stages of transition they now felt listened to by managers who were taking the time to learn about their services

7. Recommendations

The following recommendations are made:

The Governing Body is asked to:

Note the content of the report, in particular, the positive impact that co-producing service redesign with children, young people, parents and families and moving to outcomes based service contracts can have on patient experience.

Support continued collaboration with Local Authority colleagues to ensure that the lessons learned from patient experience and the CQC/Ofsted inspection are used to inform monitoring of existing services and future commissioning decisions.

8. Update on Actions Taken Following Previous Patient Stories

I. Story presented at November 2016 Governing Bodies: The actions taken to ensure an effective transfer of residents and positive experience following the closure of a care home.

Following this patient story, two more care homes have been closed in Nottinghamshire. Both closures have followed the policy and procedures followed at Hallcroft. This has ensured a smoother transfer process for residents and better communication and effective co-ordination from all stakeholders. Where suitable and applicable, the process has been revised and improved across both health and social care.

An escalation programme is currently being developed to ensure we gather information from all relevant parties where concerns are identified.

Locality manager forums have been established to share best practice and support managers of care homes.

Information sharing meetings have also been set up. These fall into 2 categories:

- Meetings with the involvement of CQC, HealthWatch, Multi-Agency Safeguarding Hub (MASH), Local Authorities and CCGs, reviewing wider aspects of care home quality across the area.
- Locality focused meetings involving the Older Adult teams, Local Authority and CCGs to share local intelligence and avoid duplication.

MASH are working to ensure effective communication of quality concerns and section 42 requests.

The Quality and Safety Leads (CCGs) for Care Homes and Home Care are developing a quality dashboard to collate monthly quality returns from care homes. This data will be analysed to determine themes and trends to assist quality and safety improvements.