Contact a Family and NHS England’s Parent Participation Project: A briefing for health colleagues

March 2016
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Acknowledgements and key partners

We would like to thank the Department for Education who have funded the Health Participation project at Contact a Family, this Participation Briefing and the facilitated workshop that contributed to it have been supported by that project. We would like to take this opportunity to also celebrate our many partnerships across NE Lincolnshire some of which are shown below.
Summary and purpose of this briefing

The aim of this short briefing paper is to promote a shared understanding of the impact and value of Parent Carer Participation at a structured and strategic, rather than personal level.

Building upon the functions and duties of the new structures set up under the Health and Social Care Act 2012, recent legislation in Part 3 of the Children and Families Act 2014 has thrown into sharp focus new legal duties on all NHS health commissioners and providers. These include those outlined in Section 26—joint working and joint commissioning arrangements, and the Section 19 duties to achieve ‘best possible educational and other outcomes’, and having ‘due regard to the views, wishes and feelings of the child or young person, and the child’s parents’; all of which will form the basis of the forthcoming SEND Joint Area Inspections by OFSTED and CQC from May 2016.

This briefing paper looks at how working strategically with NE Lincolnshire Parent Carer Forum could specifically support and provide evidence in anticipation of these inspections, but much more importantly, can support our joint and mutual goals to improve outcomes for local children, young people and their families.

Introduction to NE Lincolnshire Parent Participation Forum

NELPPF is a formally Constituted Community Group and is the collective voice for parents and carers in North East Lincolnshire, offering guidance and support from 0-25 years. We are the strategic conduit for the voice of parents across the local area.

• We ensure that parents’ views and experiences influence local services to make things better.

• We believe that by working together we can make our voices heard and raise other people’s awareness of our children’s needs and recognition of our role as parent carers. Together our views and experiences can be received more clearly and strongly.

• We include parents, grandparents and foster parents, of children and young people with any learning difficulties, complex health needs, rare disorders and genetic conditions, physical and hidden disabilities, mental health and those with sensory needs, challenging behaviour and those who haven’t received a diagnosis.

We are funded by the Department for Education and have been working in co-production with key partners across NE Lincs since 2008. The families we represent are drawn from across North East Lincolnshire with many families from lower economic backgrounds and areas of deprivation. We are aware of and monitor the Child Health Profile of NE Lincs as evidenced in the CHIMAT data and believe we have a wide, diverse and representative membership to draw on thereby providing the CCG and partner delivery organisations both quantitative and qualitative views and input from parents.

The diagram in Appendix 1 illustrates the diversity and range of our recent work.

See our new animation ‘Power in Numbers’ that illustrates the approach, ethos and ways of working that we have adopted: https://youtu.be/onyh_u_Sp_c
Context and Background to Parent Carer Participation

The National Network of Parent Carer Forums (NNPCF) was formed in April 2010 and became a formally constituted group in 2013. The Network is made up of 151 local Parent Carer Forums from across England and is a key element of the Strengthening Parent Carer Participation Programme delivered by Contact a Family (CAF) on behalf of the Department for Education.

The NNPCF has built on the participation ground work related to Short Breaks established by parent carers and CAF during the Aiming High Programme. Despite initially having only limited resources, NNPCF has now become an established and credible widely recognised national organization based on an active network of 151 local forums who between them now have over 67,000 members across England.

Further detailed background about parent carer participation, what it means, its impact and how the NNPCF has been developed, can be found in previous Progress Reports and at: www.nnpcf.org.uk/

The NNPCF membership consists of 151 local parent carer forums that are pan disability, parent led and supported by the Department for Education. NELPPF is a member Forum.

“It’s very important that we keep moving forward. People’s experiences of the system need to be positive. That’s the purpose of our reforms and we know that when parent carers, children and young people are properly involved in planning right from the start, those experiences continue to improve.”

Edward Timpson
Minister of State for Children and Families

Karen Hoe, Parent Participation Lead at NELPPF taking part in the round table discussions with Minister of State Edward Timpson
The aims of the National Network of Parent Carer Forums are to:

- Ensure that good practice, knowledge and shared expertise about parent participation continues to grow and strengthen.
- Develop a cohesive and coherent structure to sustain and develop the effectiveness of parent carer forums across England.
- Strengthen the pan disability, parent led model of local forums and boost our collective voice.

Working very closely with and supported by Contact a Family, NELPPF is one of just nine selected Pilot Sites for a DfE funded Health Participation Project to promote strategic partnership working between CCGs and Parent Carer Forums. The aim of this project is to bring participation with health partners in line with the levels of joint working and co-production that the vast majority of Local Authorities have developed preparing for and implementing the SEND reforms outlined in the Children and Families Act 2014.

“I believe in true parity for all children and young people, and am always reminded of what an amazing disabled young man called Corey says - we do not deserve to be in the shadows of society.”

Jackie Cornish
National Clinical Director for Children, Young People and Transition to Adulthood, NHS England

“The NHS England guide to Transforming Participation in Health and Care talks about listening to and acting on parent carer feedback at all stages, including commissioning and arranging; ... commissioners should publish what they have done and their evidence, it is not just about ticking a box.”

Flora Goldhill
Director Children, Families & Maternity and Health Inequalities, Department of Health

“We are far better working together than trying to do this in our separate little silos.”

Michelle Mello
Deputy Director of Nursing, NHE England
Local examples of partnership working with health colleagues

As referenced in the CCG’s own Engagement Strategy the newly published NHS England Patient and Public Participation Policy contains the NHS Ladder of Engagement and Participation (see Appendix 2).

The ladder of engagement outlines a variety of forms of engagement and participation. The policy states it is to be used as a best practice tool by NHS England staff in a flexible way to ensure appropriate and proportional participation. Using the different stages shown on the ladder, here are a few examples from the work that the Parent Participation Forum has been engaged in:

**Collaborating**

A Care Act Event with Luke Clements; the Forum co-produced this event with the CCG and Transitions Team in June 2015.

**Outcome:** This event saw some great engagement working all together, raising awareness to both families and professionals of their new rights as Carers. This has also resulted in the Forum being invited to sit down with children’s services to look at creating the local protocol for parent carer assessments.

**Involving**

The Forum were fundamentally involved in the development and planning for the new Assisted Living Building that has been recently launched; advocating for adequate changing facilities, hoists etc for disabled people as there is no provision within the main hospital building.

**Outcome:** Members of the public can come to the new purpose-built facility to find out what types of equipment are available and what they are eligible for. It will enable children, young people and disabled adults to both gain and keep being more independent. NE LINCS CCG Assisted Living Building www.nlgsi.org/services/assisted-living-centre/

**Consulting**

Forum members and young people have been involved in a public consultation over a 6 month period on the Children’s Autism Provision. The feedback is helping provide the vital ‘evidence and build ‘ phase of the Autism pathway / strategy that NELPPF are writing alongside health partners. Expected outcome: the final pathway will have a higher credibility amongst families and be much more likely to meet locally identified need.

Three simple questions were asked:

- What Works?
- What isn’t working?
- What needs to be improved?

The responses were gathered at events, workshops, schools, coffee mornings, on-line surveys, post 16 and Early Years settings amongst others.

**Informing**

The NE Lincs SEN newsletter is a prime example of local collaboration and information sharing. The Forum were the driving force in establishing this and now co-produce it with SENDIASS, NEL Council, CCG & SERCO. This is a newsletter that provides information, guidance and advice to families and young people with SEN and goes out to over 3000 people via schools, children’s centres, hospitals, nurseries and post 16, clubs etc.

**Outcome:** more parents and carers are informed and supported to be involved in, and make decisions about their child’s education, health and care across all aspects of their lives. This is a core aim of the Children and Families Act 2014.
Identified key priorities

As part of this Pilot work, Forum members attended a workshop facilitated by a Contact a Family Associate to look at national and local health structures and commissioning priorities. The table below illustrates where key priorities for both the Forum and the CCG overlap and where the Forum members can support the CCG to meet its stated strategic aims.

<table>
<thead>
<tr>
<th>NELPPF CURRENT PRIORITIES FOR HEALTH</th>
<th>NE Lincs CCG priorities</th>
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<td>The Forum is acutely aware of its new role in the forthcoming OFSTED and CQC SEND inspection framework and would like to build on NEL CCG’s innovative approaches to engagement by working with the CCG to support the local area to be ‘inspection ready’.</td>
<td>Linked by statutory duties/roles North East Lincolnshire CCG is a recognised national leader in engagement by embedding public involvement in the commissioning of health and adult social care services. Promoting continuity of care – A dedicated population-wide team will provide care for complex populations, and ensure a clinically-led coordinated approach, so each patient will be assigned the right professional to serve his/her needs appropriately.</td>
</tr>
<tr>
<td>Coordination of care is a massive issue to our families around a child’s assessments and planning of care across all the Health, Education and Social Care aspects of their life- this will be a fundamental aspect of the inspections.</td>
<td></td>
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<td>Whilst being aware that the LA commissions CAMHS services, transition to adult health services generally and in particular access to mental health services for those 18-25 with Learning Difficulties are a particular concern to Forum members.</td>
<td>Mutual goals and clear links Mental health provision will be embedded in the delivery of our integrated single point of access to ensure that there is parity of physical and mental health needs and service users receive an holistic assessment and service offering. Services for Young People experiencing mental health problems are a priority. We work in partnership with the local authority with CAMHS and have a clear transition strategy for adolescents. P 28</td>
</tr>
<tr>
<td>Families say they would like to be less dependent and much more self-reliant but that needs supporting and maintaining throughout the child’s life. The ‘crunch’ point for many families is then on transitioning from the relative security and coordination of Paediatric health to adult provision. The Forum would very much like to work with the CCG on how our young people can be supported towards independence and achieving confidence when engaging with the adult health world both at Secondary Acute and Primary Care levels.</td>
<td>Mutual goals and clear links Our 5-year strategy for maternity and children seeks to commission services which are responsive to patient need, accessible 7 days a week, safe, sustainable, provided in the community where possible with a strong emphasis on self-management and independence. P 36</td>
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Suggested ways forward

We would suggest an initial informal small, targeted meeting with CCG lead officers to scope out the following issues:

- To identify the key successes/issues/challenges regarding the new duties on health partners in the SEND Reforms
- How the Forum could support the CCG to meet their obligations around parent engagement of children and young people with SEN and disabilities and therefore be OFSTED/CQC ‘ready’
- To agree priority areas for strategic engagement with the CCG as outlined in above table
- To agree structures, named leads and timelines to take this work forward

References

4 CHIMAT Data NE Lincs file:///C:/Users/user/Downloads/ChildHealthProfile2015-NorthEastLincolnshire.pdf
Appendices

Appendix 1

Changes Due to Parent Participation in North East Lincolnshire

Appendix 2

The ‘Ladder of Engagement and Participation’

There are many different ways in which people might participate in health depending upon their personal circumstances and interest. The ‘Ladder of Engagement and Participation’ is a widely recognised model for understanding different forms and degrees of patient and public involvement, (based on the work of Sherry Arnstein7). Patient and public voice activity on every step of the ladder is valuable, although participation becomes more meaningful at the top of the ladder.

<table>
<thead>
<tr>
<th>Devolving</th>
<th>Placing decision-making in the hands of the community and individuals. For example, Personal Health Budgets or a community development approach.</th>
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<tr>
<td>Collaborating</td>
<td>Working in partnership with communities and patients in each aspect of the decision, including the development of alternatives and the identification of the preferred solution.</td>
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<td>Involving</td>
<td>Working directly with communities and patients to ensure that concerns and aspirations are consistently understood and considered. For example, partnership boards, reference groups and service users participating in policy groups.</td>
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<td>Consulting</td>
<td>Obtaining community and individual feedback on analysis, alternatives and/or decisions. For example, surveys, door knocking, citizens’ panels and focus groups.</td>
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<tr>
<td>Informing</td>
<td>Providing communities and individuals with balanced and objective information to assist them in understanding problems, alternatives, opportunities, solutions. For example, websites, newsletters and press releases.</td>
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Contact details

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(under construction)

‘If you want to know how well a pair of shoes fit you ask the person wearing them not the person who made them, or paid for them.’

Anon