

Redbridge –Bringing about transformational change in health

Parent Carer Forum: Interface

Email: info@interface-parentforumredbridge.org.uk

Web: www.interface-parentforumredbridge.org.uk

Background

The Parent Forum in Redbridge was set up by parent carers who were concerned about the health services being provided to their children with SEN and disabilities. These concerns included:

- The child development centre was based in an old and decaying building.
- There were no clinical pathways and children were waiting an extremely long time to be assessed and get help from health.
- There was a lack of multi disciplinary teams, leading to care being poorly coordinated and difficult to access and opportunities for early intervention being lost.
- Parents were not receiving preventative help, including lack of support around their child's behaviour and sleep.
- Data was not being gathered on numbers of disabled children so services were not understanding of and responsive to the needs of local families.
- This was leading to poor outcomes for the health and wellbeing of both children and families.

Interface took whatever opportunity arose to talk to everyone at all levels within the Local Authority and Health, including commissioners and providers, which led over the years to a number of things including reviews of service, input to the Joint Strategic Needs Assessment (JSNA). This brought about a few small improvements but not the transformational change that was needed.

Approaching the Health & Overview scrutiny panel

Every local authority in England and Wales has an Overview and Scrutiny committee whose members are made up of councillors. They can carry out reviews of issues of relevance to local people and make recommendations to decision makers including NHS commissioners. They have the right to refer matters back to the full council if it believes decisions have been made in contravention of the council's budget or strategy.

The Forum had a good relationship with their local authority Special Educational Needs & Disability lead and the Director of Children Services (DCS). Various joint events were organised for the Forum, health and the Local Authority to come together to discuss the issues. Following those, the Forum wrote to the DCS and asked her to seek a strategic review of health service in relation to disabled children because of a number of systemic problems.

In their letter they mentioned

- the importance of early identification and support by health and the impact on local authority services if children did not receive early intervention, citing national evidence supporting this
- the current situation in Redbridge where some children were not being diagnosed, and those that were diagnosed were being sent away with no support
- the importance of having multidisciplinary clinical care pathways for assessment and support
- the lack of clarity after the recent changes in health commissioning as to who will manage and commission this and the need for an effective health system joined up one with education and social care
- the changes being introduced at a national level which say specific arrangements need to be made for children and disabled children
- other reports supporting the case e.g. Marmot Report on inequalities and disabled children.

The Forum used evidence in their report gathered from previous consultations with members, including parent quotes to bring the letter alive.

"I had to have a breakdown to get what I needed"

"no-one should have to go through what I went through"

"I really needed the help and could not get it"

"GPs do not check wider health issues – who is supposed to do it?"

The Director of Children Services agreed to approach the local authority overview & scrutiny panel (OSC) and ask them to set up a children's disability scrutiny working group to investigate further. The OSC agreed to this.

Presenting to the children's disability scrutiny working group

Interface were invited to present to the working group. They developed a powerpoint presentation for this which included:

- a history of their attempts to get improvements made and clinical pathways introduced over the last 5 years
- an explanation of disability, SEN and neurodisability and mention of the Equality Act (2010), to ensure common understanding of relevant terminology
- how disabled children often have to access many different health services
- the role of the local authorities and clinical commissioning groups in commissioning health services following recent changes
- national initiatives supporting their case such as the Children and Young People's Health Outcomes Forum, the NHS Mandate, the Children & Families Bill
- how the current system was letting families down
- how parent participation helps improve services, and their desire to work with the Committee and others to make things better for all

- the importance of gathering data to inform commissioning of services and the lack of available data on disabled children
- the need to understand and meet the health needs of disabled children and tackle health inequalities.

Working with the children's disability scrutiny working group

Following this the Working Group co-opted two parent representatives from the Forum to be members of the Group. They visited the premises where the child development centre is based. They also visited a neighbouring child development centre in Hackney called the Ark, where different health professionals (paediatricians, therapists, nurses) work together from the same purpose built building. The Ark showed the subgroup the clinical pathways and protocols they have in place which meet the current NICE guidelines of 18 weeks from referral to assessment. This helped the councillors understand how a well run child development team operates.

The Working Group ran their own consultation of parents or carers of children with disabilities in Redbridge asking them about their views of the standards of care they received. The forum encouraged their members to respond to this consultation.

The Working Group invited key leads to attend meetings and answer questions, including leads from the clinical commissioning group, the local CDC as well as the local authority

Finally the sub-group wrote a report with recommendations and an action plan, requiring certain actions to be met by a certain date and identifying the organisations responsible for this.

The recommendations in the Working Group report include:

- the child development unit moving to different premises with all health professionals based in the one premises
- developing integrated clinical care pathways which meet the NICE guideline regarding 18 weeks
- more streamlined data collection to gather more accurate numbers of on disabled children.
- designating existing staff to be keyworkers/lead professionals
- the establishment of a Joint Commissioning Group and a child health commissioner for Redbridge
- development of a code of practice for disabled children's service to be included in the the SEND EHC/local offer
- establishment of a health working group to take work forward which includes parent representatives
- the views of parents and families are used in monitoring the services.

The report was submitted to the Overview & Scrutiny committee for adoption and the parent carer representatives were invited to present to this full committee too. The report has now been approved and is now waiting to be adopted by the cabinet (the full council). Following this approval, there will be regular reporting to the

OSC on the implementation of the recommendations to make sure they take place.

"I am very grateful to representatives from the Redbridge Interface parent carers forum who played an integral role in the development of this work and hope that parents and carers of children and young people with disabilities will see clear links between our recommendations and their experiences ."

Councillor Elaine Norman, Chair, Health Needs of Disabled Children Working group

Outcomes

- The child development team is to be provided from new premises where all the different health professional involved can take a multi-disciplinary approach to provide a 'Team around the child 'support.
- Clinical pathways are to be developed so children get seen quickly and appropriately when referred for assessments.
- The clinical commissioning group have found parents helped them in understanding the problems that were occurring and are keen to continue working with them.
- Having helped councillors understand how disability affects families, the council has agreed not to cut any disabled children services.

Why this worked

- The parent forum was structured, consistent and persistent.
- They regularly gathered evidence from their members through consultations and focus groups and used this to evidence their reports and presentations.
- Their communications were well thought out and tailored for different audiences.
- After struggling to make inroads into health they approached a strategic lead in the local authority with whom they had good relations with and asked their assistance.
- The forum used the right language for the right audiences.

Interface Powerpoint presentation to the Health & Overview sub-committee.

Forums might like to download this presentation at www.cafamily.org.uk/pcp/health and adapt for their own purposes

The final report of the Working Group with recommendations for supporting the health needs of disabled children and families can be downloaded at www.interface-parentforumredbridge.org.uk

This is one of a series of case studies showing how parents helped improve health services for disabled children. You can browse all of these in our Success Stories section at

www.cafamily.org.uk/parentcarerparticipation

Contact a Family

209-211 City Road, London, EC1V 1JN

Tel 020 7608 8700

Fax 020 7608 8701

Email info@cafamily.org.uk

www.cafamily.org.uk

Incorporating The Lady Hoare Trust
Registered Office: 209-211 City Road, London, EC1V 1JN
Registered Charity Number: 284912 Company Limited by guarantee
Registered in England and Wales Number: 1633333
Charity registered in Scotland Number: SC039169
VAT Registration Number: GB 749 3846 82