

## Hull – working with NHS Hull Clinical Commissioning Group and Healthwatch

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### Background

NHS Hull Clinical Commissioning Group (CCG) funds a parent participation coordinator to support the Forum; facilitated by KIDS. In return, the Forum agrees to carry out engagement and consultation with their members on their views and experience of health services when requested. There is a lead health commissioner for children's services who the Forum has a good working relationship with. This lead commissioner transferred from the Primary Care Trust to the CCG as part of the changes to the NHS in April 2013.

Having a good working relationship with a lead commissioner for children has been key to the Forum's success in helping improve numerous services.

Here are some examples.

### Being kept informed – working with Healthwatch

Some parents reported that they were not always copied into letters from health professionals writing about their child. This led to situations where other members of the team supporting their child knew information that the parents were not aware of. It was difficult for the Forum to raise this as an issue, as so many different health professionals from different services were involved.

Healthwatch agreed to look into this further on behalf of the Forum. They came back to the Forum and provided them with the Department of Health (DH) Good Practice guidelines on copying letters to patients, which advises patients should be copied into letters following appointments. Healthwatch also developed a form for parents to give to any health professional providing support to their child asking for them to be copied into future letters. Healthwatch asked the Forum to monitor how successful this is in resolving the issue and to come back if it continues to be a problem.

### Improved children's wheelchair service

In 2012, the Forum were asked by the PCT to undertake a review of the children's wheelchair service. Two parent representatives were then involved in the procurement of a new service. This has led to an improved service with reduced waiting times and a more efficient maintenance and repair service. The Forum receives much fewer complaints from parents about the wheelchair service, and if problems do occur, they know who to contact – including the commissioner – and the problem is usually quickly resolved.

### Development of autism assessment and diagnostic pathway

The CCG identified the need to review services for the assessment and diagnosis of children with autism and develop a remodelled service and clinical pathway so that children would be seen, assessed and parents receive the results of the assessment within 20 weeks of referral. Parents were cynical that this could be achieved but agreed to help in developing the new pathway.

Parents helped write the text for a new leaflet describing the service as well as standard letters sent to parents when children are referred. The Forum ran two focus groups with parents to get their comments on these and suggested changes to make the contents easier to understand, including using parent-friendly language.

New referrals are being processed using the new pathway and the CCG has developed targets for clearing the waiting list with the provider. The Commissioner meets bi-monthly with the Forum and provides updates and information showing how the service is performing. As a result, more children are being diagnosed earlier and appropriate support is being offered to parents.

## Sleep and behaviour

The Forum has worked in partnership with KIDS, the CCG and the Local Authority to support an initial Sleep Pilot, looking at the extent of the difficulties parents face and what can be done to support them. Following an initial pilot, a sleep project is currently being undertaken in Hull, funded through a partnership arrangement between KIDS, the CCG and the local authority. The Forum reported to commissioners that parents wanted more support to help them manage their child's sleep and behaviour.

Some staff had been trained to deliver Stepping Stones, part of the Triple P parenting programme, specifically designed to provide positive support for parents of disabled children. However, staff reported that for many parents themselves lack of sleep was a big problem. Some parents were trying to function on only two or three hours of sleep a night.

The Local Authority, health services and KIDS agreed to investigate what they could do to help families and formed a strategy and a sleep implementation group.

They invited the Children's Sleep Charity to deliver two sleep workshops to families. After the workshops, the Forum helped in monitoring what the outcomes were for families. It became clear that whereas some parents could successfully implement the strategies they learnt from the workshop others needed more one-to-one- support.

14 staff then attended a two-day sleep practitioner training and started to provide sleep support through the city. The Forum again helped in monitoring this service. They discovered that though this approach worked well for many children, it was less likely to work if the child was on medication that interfered with sleep. This is common for children with ADHD and epilepsy.

Twenty additional staff, from a range of agencies across the city have since attended a more intensive six-day sleep counsellor training, delivered by Sleep Scotland, which has included sessions on the physiology of the brain, the impact of medication (including on children with epilepsy and ADHD), as well as training on cognitive and behavioural approaches.

The Forum also helped run a conference on sleep for parents and professionals to tell them about this service. This also provided an opportunity to attract new parents to the Forum.

## Improving the Walker Street Children's Centre

Parents from the Forum were invited to give feedback and suggestions for improvements at the local Children's Centre where a range of community health, social care and education services for children with special educational needs, disabilities and/or additional health needs are delivered. Parents identified a range of issues related to the building that needed addressing. These included:

- a lack of suitable toys for children and a sensory area had been replaced with games consoles
- narrow pavements making it difficult to access with wheelchairs/buggies
- the pedestrian gate was permanently locked – so pedestrians had to walk on the main driveway to get in
- a lack of parking spaces causing significant stress for parents before they even met any supporting professionals
- a lack of hoists and changing places
- the walls were not adequate to maintain patient confidentiality.

The Forum was asked to visit the building with the estate manager to point out the problems.

They then worked with the estate manager to plan how to improve the centre.

This was agreed but before this could happen the building was flooded, meaning a much bigger refurbishment is now required.

The Forum have been invited to work with the estates department on planning this and it is thought that the flooding may actually provide more scope for improvement.

*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](http://www.cafamily.org.uk/parentcarerparticipation)**

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