

Using clinic time to hear the voice of families

Laura Crowther, a Paediatric Epilepsy specialist nurse, with support from Dr Deepa Naga (Consultant with a specialist interest in Epilepsy), led the work at Wythenshawe to hear the voices of families who attend the service. Laura did not have a lot of resources in terms of time or funds to get this work off the ground, so was looking for an approach that fitted in with existing clinical work.

In partnership with the RCPCH &Us team, Laura planned a 'clinic chat' approach. Families attending clinic on a set day were contacted and asked if they would be happy to give their feedback during the clinic. Other families that were not due into clinic that day but who were keen to give their feedback were offered a telephone call later in the day.

In total, 10 parents and 13 children and young people gave their feedback during the clinic chat and through the arranged phone calls.

Space and Voice

The clinic chat approach uses time that families are already attending clinic to engage and get feedback rather than inviting people to attend a stand-alone event. This is often a convenient way for families to provide feedback. It is in person, so more personable than a questionnaire and allows anyone who attends the service to engage not just those who are able to attend an additional session.

The clinic at Wythenshawe had a specific room available for families attending the clinic to come and have a chat with the staff member during their clinic chat but they were also able to chat in the waiting room or in the outside play area to meet the needs of the families.

The prompt questions and visuals for the discussion were deliberately kept very broad to allow children, young people and their families to identify from their perspective :

- What helps you to live healthy, happy and well with epilepsy?
- What things do clinic, schools, sports clubs etc, say, do and give, that help?
- What is one thing you would share with someone new attending the clinic that you would have found useful?

Wythenshawe Hospital, Manchester Foundation Trust

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Audience and Influence

Some key themes emerged from the families. In terms of communication, the use of WhatsApp to be able to contact the Specialist Epilepsy Nurse was seen as a lifeline and was repeatedly raised by families as something that was helpful. Another clear theme or recommendation was to develop a pack for families new to the service and diagnosis, and through the clinic chat, there is a long list of suggested contents for this pack.

Epilepsy nurse-led training at schools was raised several times which is done as and when possible. There was also a call for more for the 12-plus age range to do in the waiting room.

Some of these suggestions were endorsements for current practice (like the use of WhatsApp), whilst others would require some time and resources to take forward.

Impact

Thanks to the clinic chat and involvement in this programme, the initial epilepsy pack given to children, young people and families includes epilepsy alert cards, guides on how to video seizures and quotes from young people who are living with epilepsy.

Outpatients have now changed the layout of the waiting room, offering a space for young people away from the cartoon films and toys for younger children. In that area, there are some puzzles, books and information on transition which is better for this age group.

Other ideas are currently being explored by the team to see how things can be progressed.

**Thank you to the team for being involved in
our pilot and sharing your experience.**

**To find out more, please contact
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