Leeds - support for families on common issues e.g. behaviour, toilet training

Parent carer Forum: EPIC

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Background

- Parents told the forum they wanted advice on how to support their children around issues such as sleep, behaviour, toilet training, eating and sexuality.
- The child development team did not have enough resource to support parents on this.
- The parent carer forum asked Dr Arnab Seal, the lead community paediatrician and Sue Wilkinson, General Manager of NHS Leeds Community Healthcare, for help in finding a solution.

What they did

Dr Arnab Seal and Sue Wilkinson set up a small working group inviting the head of community care and representatives for special school nurses, therapists and parents to join.

The forum said parents did not think it necessary to be seen by a consultant paediatrician on these issues. They were happy for someone else to provide advice. The medics felt this was a better use of staff time,

The working group discovered that school nurses working in special schools could provide advice to parents on these issues. The school nurses were already doing this on an adhoc basis to parents who approached them. However many parents did not know they could go to the school nurse for this type of advice.

The working group decided to put this service on a more formal basis. It was agreed that school nurses would spend one day a week providing an advice service to parents. This was publicised to parents to let them know they can telephone the school nurses for an appointment. Children who are in main stream schools and registered as disabled can also access this service.

The community paediatricians hold some clinics in the special schools with special school nurses attending also.

Outcomes

Parents are receiving advice from people with a wealth of experience of working with disabled children who can provide strategies to parents to help them cope with these issues.

Consultant paediatrician's time has been freed up so they can spend more time concentrating on medical matters.

Children are not having to be taken out of school so frequently to attend clinical appointments.

Why this worked

The paediatrician took a proactive role in getting the right people round the table, who between them came up with a better way of working.

"Working together in this way can lead to people finding a more streamlined way of delivering services which saves money. But the main focus has to always remain centred around the needs of the child."

Sara Smithson Chair Epic Leeds

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

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