

Rutland: Finding Solutions - through dialogue with GP practice managers

Forum: Rutland Parent Carer Voice

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Background

Rutland is a small unitary authority just outside Leicestershire.

A few parents of children on the autistic spectrum reported experiencing problems when visiting their GP practice. The forum thought this might be common for other parents of children with additional needs.

What they did

- The forum consulted with their members to find out more about their experiences of visiting the GP.
- They wrote a letter to all four GP practice managers in Rutland asking them if they would be willing to meet with a few parents to hear their experiences.
- After numerous emails, the practice managers agreed a date when they could all attend. One GP practice provided a room for the meeting. The forum also invited the Learning Disability Primary Care Liaison Nurse (previously known as Health Facilitation Nurse) based in Leicester who is a member of the Learning Disability Partnership Board to attend.
- The chair of the parent forum began by reading an email from one parent describing the wonderful service she received when attending her GP surgery. She then said that this was how the majority of Rutland parents and carers felt. However, there were one or two issues they would like to discuss with the GP practice managers to see if solutions could be found.
- Once the GP practice managers realised the parents wanted to have a discussion, rather than simply criticise, they visibly relaxed and seemed much happier about being there.

What they discussed

The GP practice managers were aware of some of the issues the parents wanted to raise and were already taking steps to address them. For example, problems with the new telephone appointments system, difficulty pushing wheelchairs over the gravel surface outside one surgery.

They had a useful discussion on the following:

- 1) Children and young people requiring blood tests:** At one GP surgery all children and young people were referred to the 'baby clinic' for blood tests. Young people were unhappy about this label and some young people with autism were refusing to attend. The clinic has now been renamed.
- 2) Letting receptionists know the person has a disability from their notes:** The GP practices has introduced a system on their computers with a 'Pop-up' box which would flag up any issues once the receptionist typed the name of the individual into the system. However, the GP practices had no way of indentifying whether a child had a disability, unless they received a diagnosis at birth. This meant they were not aware of children who had autism. The forum agreed to let their members know about this system and encourage parent carers to register their child's additional needs.
- 3) Surgeries not being aware that patients are carers:** When joining the surgery there is a field on the form to be filled in if you are a carer. However, new patients who were carers did not always realise this related to them and thought it was for people working in care homes. The forum agreed to encourage their members to tell doctors that they are carers and who they are caring for, especially if their child/young person was not diagnosed at birth with a disability.
- 4) Training for surgery staff on Learning Disability/Autism Awareness:** The Learning Disability Primary Care Liaison Nurse told the GP practice managers that training was available but the surgeries needed to inform her of the training needs of their staff in order for her to meet their needs. The GP practices were keen to train staff but it was impossible to send lots of staff all on one day without affecting the running of surgeries. However, they agreed that one or two members of staff, especially new ones, could go on this training course.
- 5) Training courses for carers:** The Learning Disability Primary Care Liaison Nurse said there are courses around Health Action Plans for all parents and carers. There are also the Traffic Light Booklet (useful if you need to attend a hospital) and Emergency Grab Sheet (useful to take with you everywhere). The forum has publicised this training to their members and in the last

year there has been two workshops on Health Action Plans that members of the forum have attended. There are also workshop dates for 2014 which will shortly be publicised.

- 6) Seeing your own doctor:** Parents wanted to be able to see the same doctor when possible. All the surgeries were very keen for this as well but the GP practice managers explained why at times this was difficult.
- 7) GP Patient Participation Groups:** The GP practice managers wanted the forum to encourage their members to become members of their GP Patient Participation Groups where they could continue to have this type of dialogue. These Groups meet once every two months for approximately one hour. The forum has helped find a parent of a disabled child to sit on some of these surgeries' Patient Participation Groups.

Outcomes

- Parents are letting GP practice know about their child's additional needs which means the GP practice is better able to support them. One surgery has appointed a 'Carers Champion' who has experience of caring for an disabled child. She tries to get to know the child/young person so that the practice can better understand how they can best meet not only the needs of the child/young person but also their parents and/or carers.
- The GP practice managers learned about the problems parent experience and put processes in place to make visiting the surgery less fraught. For example, parents can wait in their car with their child until the doctor is ready to see them.
- Parents are confident that if there is a problem they simply need to mention it and the surgery will do their best to address it.
- The GP Participation Groups will hear about the experiences of families with disabled children who attend their surgery.

"I visited the GP with my son for a flu jab. When I got there I discovered there a was going to a be a long wait. I approached the receptionist and explained that my son had autism and if possible could someone come and get us when it was our turn. Unexpectedly I was quickly fast tracked to the front of the queue."

Parent

Why this worked

- The parents began the meeting by saying what was good about the service, which made the atmosphere much more amicable.
- Everyone was willing to listen and understand what the problems were for the other people in the room, not just themselves.
- By trying to have a parent of a disabled child on each GP Patient Participation Groups the conversations can continue.

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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