The Voice of Parents and Carers

To discuss how Parents of Children with Special Needs feel about Information Sharing and the Co-ordination of Care.
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What is the Study About?

This study was funded by NHS Quality Improvement Scotland. Our aim was to evaluate how well NHS Boards record information about children with special needs. This involved discovering what type of recording systems are used to maintain information on special needs children in the community.

Some parts of NHS Scotland use an information system called the Special Needs System (SNS). SNS can record information about children with special needs, their disabilities and the services they require. In addition to recording information, clinicians can use SNS to give feedback to parents and other health professionals involved with the child’s care.

SNS is currently used in nine out of fifteen NHS Boards in Scotland. Some boards have local systems, but others have virtually no means of recording electronic data at all. The main part of this project involved discovering what disability details are recorded in Scotland, whether information is recorded consistently, and if this information is used for the purpose of monitoring and planning services for special needs children.

In order to assess the situation in Scotland, it was not enough simply to evaluate the information already recorded. It was also vital that we speak to parents of special needs children to hear about their experiences and needs. We invited parents to a series of discussions (called focus groups) to hear their views on a range of issues including co-ordination of care and how information is shared (for example, how do they feel about data being shared with other agencies involved in their child’s care such as education and social work?)
How was the Study Done?

Parents from the Highlands, Glasgow, Lothian, Helensburgh and Forth Valley took part in the focus groups. Some came from areas where SNS is used, but others did not.

We asked them the following questions:

1. What information did you receive when your child was first diagnosed?
2. Do you still have to constantly repeat yourself when talking to healthcare professionals?
3. Is the information provided to you the information you expect to receive?
4. Is it enough information to make sense of your child's needs?
5. How do you describe the co-ordination of your child's care?
6. What would you change about co-ordination of care if you had the opportunity?
What was the Outcome of the Study?

Parents told us about their areas of concern, these included:

1. Family Issues

Parents reported that their main role as a parent was often forgotten. The stress and demands of caring for their child, often mean that their other children miss out on ‘normal’ family activities and interactions. Parents also reported their frustration that healthcare professionals often view their child in terms of their condition - for example, ‘a Down Syndrome child - rather than an individual.’ Comments from parents included:

‘Treat them like a person.’ (Focus Group 2, participant 5)

‘They don’t look at the whole child, everyone is just doing bits.’
(Focus Group 2, participant 7)

Parents want professionals to appreciate that their children do not live in a vacuum, but are part of a family. From the parents’ perspective, this is frequently overlooked and means that other demands on the family are not always considered alongside the medical needs of the child.
2. Realising the Efforts of Parents

Parents are usually the main providers of support to their children and healthcare professionals should recognise how stressful and demanding this can be. It can be frustrating for parents, already in a constant cycle of stress and worry of organising services and looking after their children, to feel that their efforts are not being recognised.

3. Speaking to Professionals

Parents repeatedly used the term ‘fight’ to describe their dealings with healthcare professionals. They spoke of their ongoing battles for diagnoses, resources, treatment interventions and access to services. Consequently, they were perceived as ‘battle-hardened veterans of the system’, and there was a genuine sense of a ‘them’ and ‘us’ between parents and healthcare professionals.

4. Diagnosis

Changes in medical terminology cause difficulties for parents. It is not uncommon for a child’s diagnosis to change over time, as new terms are introduced or other symptoms become more prominent. For the parent, this can be very confusing and heightens feelings of distrust between parents and health professionals.

Parents also expressed mixed feelings about the ‘labelling’ of children. While there was concern about the stigma this can cause, it was also recognised that having a label can make it easier to access health services. Having a diagnosis enables parents to access the appropriate support services, self-help groups and specialist websites. It also provides a ‘name’ to help them explain their child’s needs to others.

‘I personally like labels, both professionally and maternally because I think it lets you look in the right places such as on the internet for information on your child’s condition. It also lets you get in touch with other parents and join the right support groups…but it is getting the professionals to look beyond the label. You have to look at the child.’
(Focus Group 2, participant 7)

‘I’ve never been a big fan of labelling kids with any particular…you know, description of sort. But what we found was that when we moved
two years ago, we have really struggled to get support. So now we are pushing for a diagnosis because we feel that without it we are just not getting the support at all.’ (Focus Group 4, participant 17)

The final comment reported was the assumption that parents can ‘cope’ with this information without need for any further support but parents feel that more information at diagnosis would have been helpful.

5. Fairness

There was an awareness of the lack of fairness in services. Parents expressed concern for other mums and dads who are ‘non-literate’ or less assertive when trying to access services. Many parents stated that you do not get the services unless you ‘shout loud enough.’

6. Where you Live

Geographically, there appeared to be differences in access to healthcare services. Some parents are offered services they do not need whereas others are turned down for services they desperately want. Parents commented that this has a direct effect on their child’s health, well-being and ongoing development.
7. What Information do Parents Get?

Parents told us that they received very little clinical or service information initially from healthcare professionals, regardless of whether SNS was used or not. Many parents felt they would benefit from having access to a specific healthcare professional that can offer support and guide them through the service system.

‘You need an information pack and you need a person, a professional that can come to you and explain things.’ (Focus Group 4, participant 20)

Many parents also reported that they had initially been ‘promised’ leaflets or written documentation that failed to appear.

‘I got very little information. Nobody sat down and told me what cerebral palsy is! It was through my own research. Thankfully, I am a very pro-active parent.’ (Focus Group 2, participant 5)

However, some parents were more fortunate than others:

‘We had very little information at the start. We got in touch with the Down Syndrome Association, but no one told us how. However, then we were very fortunate that our paediatrician had a particular interest in Down Syndrome and we got the information that way.’ (Focus Group 3, participant 7)

8. Repeating the same thing Time after Time

Much of the dissatisfaction felt by parents came from having to repeat their child’s basic case history, often going back to the birth.

‘A lot of mums say they keep on having to tell the same story over and over again…now I don’t answer questions I don’t want to, I just tell them to look at his notes.’ (Focus group 5, participant 17)
For most parents, the repetition of information seems unnecessary, particularly when they are attending a basic medical examination. Parents viewed this continual repetition as evidence of healthcare professionals being unprepared.

9. Transmission of Information

It was felt that the transmission of information is not from the healthcare professional to parent, but parent to healthcare professional. In some cases, where children had rare chromosomal disorders the consultant or paediatrician had little or no experience of that particular disorder. In these cases the parents became the experts on their child’s condition and were often asked to speak to medical students and other parents about it. Feedback from parents suggested that this role was not fully appreciated by professionals, who did not appear to recognise the difficulty it created.

10. Sharing Information

Parents expressed positive feelings on the sharing of information about their child’s care with other professionals, both within healthcare and across other services.

‘Sharing of information is a good concept but it depends on whether they look at the information.’ (Focus Group 2, participant 5)

‘Until all the services come together and people start sharing information, it’s never going to work.’ (Focus Group 5, participant 16)

It was suggested, however, that parents should see information before it is shared so they can ensure it is accurate. The inclusion of incorrect information is frustrating for parents, even more so when it is duplicated. Parents also feel they should have a say about what information should be shared.

‘I think we should be asked if we want to share the information. I don’t think it should be presumed that it should be shared. We actually know our children better than anyone else but people seem to presume that they know better than we do.’ (Focus Group 4, participant 17)
At present, parents seem to have little knowledge of who has access to their child’s medical records or how that information is being used. They suspect that a medical record is used as a *place* to hold all the information, rather than as a vital tool for sharing information.

11. Information Recommendations

There was a desire to have a *known* point of contact, someone who could guide and advise parents at any time. It was reported that many patients stumbled upon particular services through *luck* or after speaking to other parents. Parents were often simply sent home and told to get in touch if they had any difficulties and there did not appear to be any follow-up or tracking of their child after they left hospital.

12. Co-ordination of Care

There was little evidence of co-ordination of care. Essentially parents are the co-ordinators of their child’s care. This is incredibly stressful for parents and something that has to be learned over time. All felt that they were doing a good job, with little or no training. Most found support from other parents, rather than from healthcare professionals.

*I think any co-ordination of care, if you are a parent with a child with special needs, you co-ordinate it yourself.* (Group 5, participant 18)

There was some debate as to whether parents would be happy to hand over responsibility for co-ordinating care to healthcare professionals. One of the main problems is the rapid turnover in staff. Many parents develop a relationship with a particular healthcare professional, only to see them move on to another service. This is disheartening for parents who are then faced with having to build a new relationship with another healthcare professional.
Conclusions

It is clear that parents have many frustrations with the co-ordination of care, provision and access to services for children with special needs in Scotland. Many of these difficulties cannot be changed purely by an effective information system that can record and share data electronically, although this would help remove some hurdles (such as reducing repetition of information when a family moves from one NHS Board to another). There needs to be more time given to improving the management, control and regulation of the following:

- A main point of contact
- Information distribution at diagnosis
- Co-ordination of care
- Access to services
- Communication

The information produced as part of this project will be used to help healthcare professionals improve the way they record and share information. It will also be used to encourage greater communication and co-operation between parents and paediatric service providers in Scotland.