

Research Summary

How could communication between staff and disabled children in hospital wards be improved?

This research summary was written by PenCRU and members of the PenCRU Family Faculty

Key findings

- We asked parents and health professionals about their experience of communication with disabled children in hospital wards, such as what helped, and what does not help communication.
- Barriers to communication were staff lacking time, shift work, or not taking responsibility for communication, and information not being shared between parents and health care professionals.
- Communication was better when staff took time to learn about a child and built a rapport with them, had good relationships with the parent or carers, used communication aids where appropriate, and had a family-centred approach to providing health care.

Who carried out this research and why?

The research was led by researchers at the University of Exeter Medical School and paediatricians at the Royal Devon & Exeter NHS Foundation Trust.

Why is this topic important?

Effective communication is vital to enable people to understand choices and make decisions about their care. This is a fundamental human right, supported by the United Nations Conventions relating to children, and persons with disabilities.

Disabled children have to stay in hospital more often than other children. [Previous research](#) suggests that how staff communicate with disabled children when they stay in hospital affects whether they have a good or bad experience of being on a hospital ward. It also influences whether parents feel able to leave their children while they are in hospital.

What was the purpose of the research?

This study aimed to understand the experiences of ward staff and families regarding communication. Then, to use this information to identify barriers to good communication and ways that staff could improve the way they communicate with children. [This study is part of a larger project](#) in which clinicians, researchers and parents of disabled children are co-developing training for hospital ward staff that seeks to improve communication with disabled children.

How were families involved as researchers?

Parents from the [PenCRU Family Faculty](#) were part of an advisory group with nurses and paediatricians. They were involved in deciding how best to recruit participants, designing the information sheets, formulating the questions that we asked participants, and helping to interpret the findings from the analysis. Parents are also helping to tell people about the research.

What did we do?

This type of study is called qualitative research. This approach is used to find out people's views, beliefs and experiences, using interviews or focus groups.

We recruited participants through children's wards in two district general hospitals in England. Parents were eligible if their children were aged 5-18 years, had communication difficulty, and had been admitted to hospital in the previous month. Clinical and non-clinical staff were eligible if they worked on one of the two paediatric wards taking part in the study.

We carried out face-to-face interviews with parents and nurses, and focus groups with doctors and other health professionals. We developed topic guides so that all participants were asked the same questions.

For parents, topics included their general experience, examples of good and poor communication, and any changes that might improve communication.

For staff, topics included views on existing standards and policies relating to communicating with children, how communication difficulties are identified and recorded, examples of good and poor practice relating to communication, and information about training that was available for staff in this area.

What did we find?

We identified six themes. Both parents and health care professionals talked about 'not having enough time', 'prioritising communication', 'parent-professional relationships' and 'knowing the child'. Staff also talked about their 'professional world'. Parents also talked about their 'child's eye view', which was how their child experienced hospital.

Within the six themes, we identified barriers to effective communication, and also some factors that helped to improve communication.

Barriers to communication

Time pressures:

Parents identified that professionals were busy, and that they often 'gave up' trying to communicate with their child because they did not have the time. Staff were aware that communication was important but felt that sometimes there just wasn't the time to do everything. Some staff accepted this as the way it was; whereas others expressed guilt and regret.

Prioritising communication:

Some clinicians viewed diagnosis and treatment as their priority; they relied on parents, nurses or other staff such as play therapists for communication. Parents were aware that professionals often relied on them, and some parents felt unable to leave the ward because no one would be able to communicate with their child.

Not sharing information:

Parents and nurses talked about the importance of sharing information about a child's additional needs and how they communicate. Parents felt that they were not always asked for advice; some nurses felt that parents were reluctant to share information. Nurses perceived the stress and anxiety a parent might experience while their child was in hospital might be a reason information was not exchanged. Shift work patterns can be a barrier to sharing information. Some parents found it difficult to give personal information to a stranger.

Things that improve communication

Learning about the child:

Getting to know a child's individual needs and preferences helps communication. Parents are a key source of information for staff to get to know their child. Staff may also know a child because they have been in hospital before, or from another setting.

Building rapport:

Good relationships between staff and children are often based on personalising communication, such as finding out something the child is interested in. Parents suggested their child was often more relaxed and comfortable when staff took time to build trust and rapport with them.

Using communication aids:

Staff were aware of tools that might be used on the ward to help with communication but seemed unclear or not confident about using them. 'Communication passports' – a document that describes briefly how children communicate - were mentioned by parents and staff but did not appear to be used often.

Family-centred approach:

Parents and nurses thought communication was better when staff were more positive and focused on the needs and experience of the whole family.

How are the findings useful?

The findings from this study build upon work by others to help us to understand how the ward environment affects communication, and interactions between families and staff.

The participants and also the parents who were involved as researchers thought both staff and parents shared responsibility for improving communication with disabled children.

The findings have helped shape a parent-delivered training package for ward staff. The package involves two aspects (a) a one hour training session, and (b) a review of adherence to NHS and hospital policies. The training session for staff aims to create empathy and understanding, awareness that taking time to find out how children communicate can save time later, and provide practical tips.

There are time pressures on staff, and a balance must be struck between their clinical roles and their duty to provide respectful and supportive care. However, lack of time cannot be an excuse for poor communication. Much can be done to improve the knowledge and skills of staff to improve their communication with disabled children. This is now a standard requirement of the Care Quality Commission in England.

Limitations

The main limitation to this research was that children's views were not represented. We did seek to consult children directly; however, we experienced difficulty in recruiting children and the few that we did consult, with support from a familiar communicator, expressed views that were not possible to bring together with those of parents and hospital staff.

What's next?

A training package for ward staff has been developed from this research by clinicians, researchers and parents of disabled children. The package is being trialed with groups of hospital ward staff. This has helped us to learn from, and refine the training package, further.

The next stage of the research is to see whether the training package really does make a difference, and make it possible for staff on other hospital wards to undergo the training and review whether they are adhering to hospital policies and mandatory NHS care standards.

Who reviewed our research?

The research paper is published in an academic journal called Health Expectations. Before the journal accepted the review to be published it asked two independent experts to look at the paper and decide whether the research had been carried out properly and reported clearly, and whether it was important enough to publish.

The full version of the study is published in the journal [Health Expectations](#).

If you would like a copy please contact us at pencru@exeter.ac.uk

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