



## Research Summary

# In hospital and out of reach – the perceptions of disabled children

### Key messages

- We looked at all qualitative studies of the inpatient experience of children with a chronic health condition or a neurodisability
- A child's experience as an inpatient depends on communication, emotion, environment and confidence in the staff
- However, there is relatively little research which includes the voices of children with a range of different communication impairments
- This was the first phase in a programme of research to improve communication with disabled children on hospital wards
- Following interviews and focus groups with parents, staff and children with a communication impairment we are developing training for paediatric ward staff

### Who carried out this research and why?

The review was led by the team at Peninsula Cerebra Research Unit (PenCRU), a childhood disability research unit at the University of Exeter Medical School.

The research was supported the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for the South West Peninsula – known as PenCLAHRC.

The idea to carry out research about communication between paediatric ward staff and children with communication impairments came from a parent member of the PenCRU Family Faculty. Local paediatricians also acknowledged this as a concern.

### Background

Disabled children tend to be more frequently admitted to hospital than other children. There is guidance which advocates that disabled children should be consulted about their care and involved in decisions that are made about them or their treatment.

It is not clear whether this guidance is being put into practice; there is relatively little research which explores the experience of disabled children as inpatients.

### What did we do?

This type of research is called a structured review and qualitative synthesis. In a qualitative synthesis the researcher systematically searches for studies addressing a particular research question and draws together the

findings from individual studies. We used themes to summarise the data.

Qualitative research uses methods like focus groups and interviews to explore people's beliefs, experiences, attitudes or behaviours. Quantitative research uses methods like surveys and clinical trials to measure or count things. In this review we were only interested in qualitative research.

### Searching for evidence

We searched online libraries for all the research papers which have been written about the inpatient experience of children with a chronic health condition or neurodisability. We looked at over 5000 references and filtered out the ones which did not meet the selection criteria.

### Who reviewed the research to make sure it was done well?

The review is published in a journal called *Child: Care, Health and Development*. Before the journal accepted the review to be published it asked independent experts in the field to read the paper and decide whether it had been done properly and whether it was important enough to publish.

### What did we find?

#### What types of study were included?

- 8 papers were included in the synthesis
- The age of the children whose experience was the focus of the study ranged from 3-17 years of age
- Seven studies gathered the views of children, three the views of parents and two the views of nurses; some studies gathered the views of a combination of respondents.

#### What did the studies find?

Children in the included studies had a learning disability or a chronic condition requiring regular hospital admittance. Our report only includes the findings of these 8 studies so we have to be careful in our interpretation, especially as not all of the children included were disabled.

Four themes were identified as having an impact on the inpatient experience of children. These were

Communication, Emotion, Environment and Confidence in Staff.

### Communication

Communication was the main issue for children and parents, and was also described as a cause for concern by nursing staff.

#### Children

Aspects of communication that had a positive impact on children's inpatient experience included:

- Staff being friendly, helpful and reassuring
- Procedures and treatments being explained to them
- Being familiar with the hospital staff
- Honesty from staff when procedures might be painful
- Being praised if they were brave
- Nurses who used humour and joked with them

Good communication made children feel special, brave and listened to. They felt less anxious and more respected if they were provided with information and consulted.

Conversely, children were upset or frightened by:

- Feeling that staff were controlling
- Things not being explained to them
- Being left out of information and decision making
- Staff using language that they could not understand
- Questions being directed at their parents and not them

#### Parents

- Parents knew that being involved in making decisions was important to their children but felt that they needed support and didn't want to burden them.
- Some knew that their children understood more than the staff assumed but thought that staff made an effort to try to involve their children and appreciated that it could be 'difficult'.
- Parents wanted better communication between themselves and the staff; if information was not shared then they felt out of control.

## Nurses

- Nurses were not consistent about involving children in discussions and decisions; they relied on their perception of each child's ability to decide how much to involve them.
- However, they were unsure how to establish the child's ability.
- Nurses felt that parents sometimes prevented them from communicating with a child
- Children who were very knowledgeable about their condition could be challenging to nurses

## Emotions

- Children talked about feeling anxiety, relief, happiness and worry about going into hospital
- 'Good' experiences of hospital could help children to feel less anxious
- Children did not like being separated from their families
- They worried about the effect that being in hospital might have on their friendships and education
- The admission process made children, parents and nurses feel anxious; it is an unknown situation where nobody knows what to expect

## Environment

- Links to home life, i.e. food and games, and having their own space often had a positive effect on a child's experience
- Interacting with other children and becoming friends with others who were often in hospital was important
- Some children felt they lacked control and independence over when they slept, ate and drank
- Children talked more about the ward environment and how they interacted with staff than they did about medical procedures which suggests these things were more important to their experience

## Confidence in staff

- Staff showing competence, knowledge and being organised was important to children

- Children talked about the how clean nurses were in relation to their safety and how vulnerable they were to infection
- The appearance of nurses and doctors was important to children; when staff looked like a 'typical', traditional nurse or doctor they had confidence in them
- They appreciated honesty, friendship, courtesy and trustworthiness
- Knowing that the staff were working to make them better helped children to cope with procedures
- Parents also wanted to feel confidence in nurses
- Parents were less confident in staff when it was not clear how much they should be involved in their child's care while they were in hospital.

## In conclusion...

- When disabled children spend time in hospital the experience is not always as good as it could be
- Communication with staff was the main issue and could make the difference between a good and a bad experience for a child
- Communication with hospital staff could also have a positive or negative impact on the other themes – Emotion, Environment and Confidence in Staff
- There is limited research which has focused on the experience of the young person; parents' experience is often the focus
- Because of the lack of research, we couldn't separate different conditions and healthcare needs, which might have been helpful
- Not many healthcare professionals were included in these studies
- Training healthcare professional to communicate better with disabled children could improve the inpatient experience for children and families, and increase staff confidence in caring for disabled children

## What next?

### *Further Research*

This study recommends that some further research needs to be carried out to:

- hear the voices of healthcare professionals

- see whether things like communication skills training for staff has an impact on the experience of children and families and the confidence of staff working with these children

*What has happened since the review?*

- We have carried out interviews and focus groups with parents, staff working on children's wards and children with a communication impairment to find out more about their experiences

We are working towards developing some training for staff working on children's wards

- The content of the training will be based on what we have learnt from this review and from our qualitative interviews and focus groups
- A Steering Group made up of parents, paediatricians, nurses and researchers will guide the development of the training.

The full version of the structured review and qualitative synthesis is published in the journal *Child: Care, Health and Development*. If you would like a copy please contact us at [pencru@exeter.ac.uk](mailto:pencru@exeter.ac.uk)

The team that carried out the review are: Val Shilling, Vanessa Edwards, Morwenna Rogers and Chris Morris.

The research team are all part of the Peninsula Cerebra Research Unit and/or the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care of the South West Peninsula (PenCLAHRC) at the University of Exeter Medical School.

This research is funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care of the South West Peninsula (PenCLAHRC), and the charity Cerebra. The view and opinions expressed in this paper are those of the authors and not necessarily those of the NHS, the NIHR, the Department of Health, or Cerebra.