Research Summary

Improving disabled children’s experiences in hospital: a training package for hospital staff

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

Key findings

- Clinicians, researchers and parents of disabled children have co-produced a training package for hospital staff to improve staff communication with disabled children when they are inpatients.

- The training is for all staff who come into contact with disabled children during their hospital stay, including clinical and non-clinical staff.

- It is peer-delivered and contains videos of parents’ experiences of their child’s care which are used for reflection and discussion by staff in a 50 minute, one-off training session.

- The training package was delivered at Royal Devon & Exeter Hospital on four occasions. 80 staff from different professions participated in the training. Participants rated the training highly.

- The training shows potential for improving staff communication with disabled children and will be tested in other hospitals.

Who carried out this research and why?
The research was led by researchers at the University of Exeter Medical School and staff at the Royal Devon & Exeter NHS Foundation Trust.

Why is this topic important?
Disabled children typically spend more time in hospital than children who are not disabled. They often have difficult experiences in hospital, particularly in relation to their involvement in the decisions that affect their care.

Parents of disabled children and NHS staff who work on children’s wards agree that communication between staff and disabled children is a vital concern. Good communication can help reduce emotional distress and contribute to a more positive experience for children in hospital. Poor communication, on the other hand, can leave children feeling frightened and anxious such as if treatments are not explained to them.

NHS staff find communicating with disabled children challenging, especially in the context of a busy ward. Challenges to communication with disabled children raised by staff included time pressures, low priority, lack of information about individuals’ communication needs and lack of experience and training.
Two plain language summaries describe our earlier work on this topic:

- Our review of previous research on the experiences of disabled children as inpatients showed communication is crucial.
- Our interview study with parents of disabled children and clinicians identified barriers and enablers to good communication.

What was the purpose of the research?
Clinicians, researchers and parents of disabled children co-developed a training package for ward staff. The training aims to improve communication with disabled children and so improve their experience of care when inpatients. This summary explains how the training was developed and tested at a hospital in Exeter.

How were families involved as researchers?
Parents from the PenCRU Family Faculty were part of an advisory group with paediatricians and nurses. Parents were involved in the design of the training and also recorded their experiences of their child’s care on videos. The video clips are shown to hospital staff as part of the training.

What did we do?
We followed a procedure called Intervention Mapping to design the training. This involves working out what needs to happen in order for staff to participate in the training and improve their communication with disabled children.

What are the aims of the training?
The training is for all staff who come in to contact with disabled children during a child’s stay in hospital in order to improve communication in routine interactions that occur. This includes receptionists, cleaners and porters, as well as doctors, nurses and allied health professionals.

The training aims to encourage empathy and promote confidence and responsibility in relation to communicating with disabled children so that staff prioritise and practice good communication. It also aims to change the culture of the ward so that it is normal to prioritise communication with disabled children.

What is the training?
With these aims in mind, and to maximise participation by staff of different professions, we developed a training package with the following features:

- It is a low resource 50 minute session.
- It is peer-delivered by a doctor and a nurse.
- It uses video clips of parents talking about their experiences of communication when their child has been in hospital to prompt reflection and discussion by staff.
- It teaches 4 simple messages that aim to make a real difference to disabled children and their families:
  - Ask the parent or carer for advice about how to communicate with their child.
  - Find out how a child communicates yes and no.
  - Talk with the child, not just the parents.
  - Feel comfortable to admit when you don’t know the best way to communicate.

These messages are contained within the videos of parents’ experiences and are also displayed in poster format on the ward as a reminder to staff after the training.

A manual has been produced which provides facilitators with instructions and scripts for the session using the videos. It provides strategies for delivering and promoting the training, such as engaging with a hospital’s Patient and Carer Experience Group to prioritise the training at senior management level and discussing the training with managers of different professions so they give permission for staff to attend.

At the end of the training session, participants are asked to reflect and write down how they will change their practice. They are also asked to provide feedback about the training.
How was the training received by staff at the Royal Devon & Exeter Hospital?

80 staff participated in one of four training sessions at the Royal Devon & Exeter Hospital. Participants included doctors, nurses, physiotherapists, play therapists, housekeeping staff, catering staff, ward administrators and teachers. The pie chart shows the numbers of training participants from different professions.

Participant feedback was very positive. Participants found the videos of parents’ experiences helpful for understanding the impact of communication on children and their families. They also liked working together with different professions on the same topic.

Participants suggested some improvements, like having more time for discussion and focusing less on parents’ bad experiences. The training has since been revised to include more time for discussion and adding more positive parent’s experience of communication.

When participants were asked ‘how will you change your practice?’ at the end of the training, their answers showed that many participants were committed to change in different ways, they said:

- ‘Considering the patient as an individual’
- ‘Feel more confident to just ask’
- ‘Not feel bad about asking for interpretation’
- ‘Being more aware of different ways to communicate’

What does the study tell us?

The academic paper describes the development and testing of a training package in one hospital. The study showed that the training could be delivered and was well received by staff from different professions. It also suggested that many participants intended to change the way they communicate with children following the training. We do not know from this study whether the training did change communication and improve disabled children’s experiences in hospital.

What’s next?

The next stage of the research will investigate how the training can be delivered in other hospitals using the manual and the film we have produced. After we have tested delivery of the training in a few other hospitals, we can see whether the training really does make a difference to disabled children and families.

Who reviewed our research?

The research paper is published in an academic journal called BMJ Paediatrics Open. 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 BMJ Paediatrics Open.

If you would like a copy please contact us at pencru@exeter.ac.uk
The team that carried out the research are Rebecca Gumm, Eleanor Thomas, Claire Lloyd, Helen Hambly, Richard Tomlinson, Stuart Logan and Christopher Morris.

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