

Research Summary

Families views on most important health outcomes for children and young people with neurodisability

Key messages

- We consulted children and young people with neurodisability, and separately with parent carers, about which aspects of health were most important.
- Aspects of health most valued were: communication, mobility, pain, self-care, temperament (mood and anxiety), relationships, community and social life, emotional wellbeing, self-care, independence and future aspirations.
- Parents also felt their child's sleep, behaviour, and safety were important.
- Identifying these key outcomes helps to identify what health services should seek to achieve, and provides valuable information for clinicians, commissioners and policymakers.

Who carried out this research and why?

The research was led by members of the Peninsula Cerebra Research Unit (PenCRU) at the University of Exeter Medical School, the Council for Disabled Children (CDC) at the National Children's Bureau, and Social Policy Research Unit (SPRU) at the University of York.

The National Institute for Health Research funded the research. This is the Government organisation that funds health related research in the UK.

What are health outcomes?

The quality of NHS care is being assessed increasingly using Patient Reported Outcome Measures (PROMs). These are questionnaires that measure a person's own views of their health at a moment in time. Bringing together groups of responses provides one way to assess whether services are improving health.

What is neurodisability?

Neurodisability describes a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular

system and create functional limitations. A specific diagnosis may not be identified. Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion and behaviour. If you are reading online, you can find out how this definition was developed [here](#)

Children and young people with neurodisability are among the most frequent and intensive users of health services.

What was the purpose of the research?

This research aimed to find out which aspects of health families think are most important to measure as outcomes for children and young people with neurodisability conditions.

The findings will help to ensure that questionnaires used to measure health outcomes ask about things that are important to children and young people with neurodisability and parent carers.

How were families involved as researchers?

Five parents from the PenCRU Family Faculty met with researchers at various stages. They helped to decide how we could ask questions in a way that people taking part in the research would understand, and reviewed the findings from the research. They also helped to write this summary.

What did we do?

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

How did we gather people's views?

CDC advertised the opportunity to take part to children and young people through the Making Ourselves Heard Network, and parent carers through the National Network of Parent Carer Forums.

Participants were from across England, the children and young people who took part were 8 to 25 years old; some of the parents had younger children. A wide range of neurodisability conditions was represented.

People's views were gathered in focus groups or interviews. A small number of non-verbal children were able to take part using their Talking Mat Boards.

We used slightly different methods with children and young people and the parents, to try to make the topics we were asking about as accessible as possible. We showed some examples of questionnaires.

All the conversations were recorded and typed up. We took photos of things people wrote on the example questionnaires, and of the Talking Mat Boards.

What did we find?

When we looked at the data, we found that children and young people and parents did not talk about single aspects of health on their own. People in the research talked about aspects of health because of the way they link together.

We found that some aspects of health were valued more than others because they enabled 'higher-level' outcomes. For example, communication was a highly valued aspect of health in itself, but also because

communication enables children and young people to express preferences and make choices.

The team mapped all the relationships between aspects of health to find common themes. These maps showed how the different outcomes affected each other, and how they were related.

The key health outcomes were: communication, mobility, pain, self-care, temperament (mood and anxiety), relationships, community and social life, emotional wellbeing, independence and future aspirations. Parents also felt sleep, behaviour, and safety were very important.

Limitations

In this research we grouped together various different conditions under the umbrella of neurodisability. The list of key outcomes from this study may not include some key issues that might be important for children and young people with particular diagnoses.

Who reviewed our research?

The research paper is published in an academic journal called BMJ Open. The paper is [freely available](#). Before the journal accepted the review to be published it asked two independent experts to look at the paper and decide whether it had been properly carried out and reported clearly, and whether it was important enough to publish.

What next?

This summary describes how we consulted children, young people and parent carers, about which aspects of health are important to measure.

As part of the same research study we also asked health professionals which aspects of health they try to influence, and we looked at whether existing questionnaires measure the key health outcomes. We will publish summaries of those studies when they become available.

The list of key health outcomes contributes to a vision of what health services might seek to achieve, and provides valuable information for clinicians, service commissioners and policymakers.

The full version of the study is published in the journal BMJ Open

If you would like to access a copy, the full text is freely available [here](#) or contact pencru@exeter.ac.uk

The team that carried out the review are: Amanda Allard, Andrew Fellowes, Valerie Shilling, Astrid Janssens, Bryony Beresford, and Christopher Morris.

The research team are members of the Peninsula Cerebra Research Unit (PenCRU) at the University of Exeter Medical School, the Council for Disabled Children (CDC) at the National Children's Bureau, and Social Policy Research Unit (SPRU) at the University of York.

This study was part of research funded by the National Institute for Health Research (NIHR) Health Services and Delivery Research programme (Project 10/2002/16 <http://www.nets.nihr.ac.uk/projects/hsdr/10200216>). The work also benefited support from NIHR Collaboration for Leadership in Applied Health Research and Care of the South West Peninsula (PenCLAHRC), and the charity Cerebra.

The views 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.