



Research Summary

What are professionals trying to achieve for children and young people with neurodisability?

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

Key findings

- 262 health care professionals participated in at least one of four rounds of an online survey.
- Health professionals target all aspects of health (physical, emotional and social wellbeing).
- Health professionals rated the following as the primary responsibility of health services: pain, hearing, seeing and vision, mobility, communication (including speech and language), sleep, emotional wellbeing (including regulation of emotion), toileting, self-care and sexual health.
- Key outcomes recommended to measure were: mental health, confidence/emotional stability, anxiety/attention, sleep, pain, toileting, movement ability, manual ability, acquiring skills, communication, mobility, self-care, recreation and leisure.

Who carried out this research and why?

This research was part of a project examining what health outcomes should be measured for children with neurodisability. One stream of research focused on identifying what it is health care professionals target when treating children and young people with neurodisability.

This study was led by researchers at the Peninsula Cerebra Research Unit (PenCRU) at the University of Exeter Medical School in collaboration with two paediatricians, and four parents from the PenCRU Family Faculty. The PenCRU Family Faculty is several hundred parents of disabled children, mostly resident in Devon, who have indicated a willingness to be involved in research (see www.pencru.org for more information).

The project was commissioned by the National Institute for Health Research (NIHR).

Background

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](http://ow.ly/xb4wa) (or use this link: <http://ow.ly/xb4wa>).

Children with neurodisability are often frequent and intensive users of the health system; they have contact with a broad variety of health care

professionals. These professionals do not seem to share the same vision, and have differing views of their responsibilities and role in relation to children and young people.

Currently, performance indicators are being used to examine and compare achievements across health organisations. Hence, identifying the aspects of health that clinicians are seeking to change would be extremely helpful.

What did we do?

The method we used is called a Delphi survey; it is a method to reach consensus, or agreement. Participants are presented with statements and asked to rate their agreement or disagreement, and make comments.

The researchers collect the answers and use the feedback to reformulate the statements and then present them again to participants. The process is repeated until at least 67% of the group agrees.

Which professionals were included?

We sent out invitations through child development teams and specialist professional societies in England. Health care professionals volunteered to participate by registering online.

In total, 295 health professionals registered interest in taking part; 233 took part in round 1, 232 in round 2, 227 in round 3 and 191 in round 4. Participants were from a wide range of professions: e.g. nurses, orthotists, paediatricians, physiotherapists, psychologists, surgeons, and speech and language therapists.

How did we analyse the data

Responses from round 1 were organised using the components of health proposed by the World Health Organization.

Comments and feedback in each round were categorised, and discussed by the team to inform further rounds of the survey.

What did we ask and what did we find?

The questions in the first round were very open and broad. The questions became more specific in later rounds as we learned from what participants told us.

- Round 1 -

We asked: what aspects of health are you trying to influence/improve when working with children and young people with neurodisability?

233 professionals answered the survey; in total we received 1524 separate suggestions. As a group, respondents targeted all aspects of health: emotional, physical and social wellbeing.

- Round 2 -

We presented a list of the 20 most frequently mentioned aspects of health, and asked:

- 1) *To what extent do you agree that the list broadly includes some of the aspects of health you target in your professional work?*
- 2) *Do you agree this list covers broadly the health outcomes that the NHS should assess routinely for these children?*

(strongly disagree, disagree, agree, strongly agree)
A free text box to provide feedback on the list.

211/232 (90.9%) of respondents agreed or strongly agreed that the list broadly included some of the aspects of health they target;
207/232 (89.2%) agreed or strongly agreed that these were appropriate health outcomes for the NHS.
The list was revised based on the comments received for use in round 3.

- Round 3 -

We presented a revised list (see below), and asked:
Would you agree that this list now represents appropriate NHS health outcomes for children and young people with neurodisability?
 (strongly disagree, disagree, agree, strongly agree)
To what extent do you think health care should target

- *Functioning (what children can do)*
- *Wellbeing (how children feel)*



209/227 (92%) agreed or strongly agreed that the revised list contained appropriate NHS health outcomes for children and young people with neurodisability.

Most professionals said they targeted both functioning and wellbeing:

- Functioning: 212/227 (93.4%)
- Wellbeing: 190/227 (83.7%)

List of aspects of health as presented in round 3

Mental functions: e.g. mental health issues
Consciousness functions e.g. seizures, stroke
Temperament and personality functions: confidence, emotional stability
Sleep
Specific mental functions: e.g. anxiety, attention
Psychomotor control: e.g. behavioural problems
Pain
Functions related to digestive system: e.g. constipation, swallowing, drooling
Urinary functions (continence, enuresis)
Neuromusculoskeletal and movement: gross and fine motor function; quality of movement
Mobility of joint functions: e.g. mobility and ease of movement of joints
Muscle power functions: muscle strength
Muscle tone function: e.g. spasticity
Control of voluntary movement functions: e.g. movements, head and trunk control
Learning and applying knowledge: acquiring skills; learning to read, write
Acquiring basic skills: e.g. fine motor function to improve eating, pencil holding
Communication
Changing and maintaining body position: e.g. sitting, standing, lying down
Mobility (in Activity and Participation): e.g. moving, making transfers between posture
Self care: e.g. independence in all activities of daily living (washing, toileting, dressing, eating)
Community, social & civil life: e.g. engaging in social clubs; recreation and leisure
Movement (Body Structures & Functions): e.g. gait, deformity; muscle length and joint range of movement

- Round 4 -

We asked:
To what extent you think the NHS should be responsible for each of the following 23 aspects of health from questionnaires that assess quality of life from a patient's perspective
 (on a scale from 1 to 7: 'not at all' to 'completely')



NHS more responsible for: pain, hearing, seeing, vision, mobility, communication, movement and manual ability, sleep and toileting.
 NHS less responsible for: play, relationships with family, sport and leisure, learning and applying knowledge, and relationships with friends.

What do these findings tell us?

Professionals broadly agreed on a core set of aspects of health that are primary concerns for health services: pain, hearing, seeing and vision, mobility, communication (including speech and language), sleep, emotional wellbeing (including regulation of emotion), toileting, self-care and sexual health. Professionals perceived health services to be less responsible for social and well-being outcomes.

Key outcomes recommended to measure were: mental health, confidence/emotional stability, anxiety/attention, sleep, pain, toileting, movement ability, manual ability, acquiring skills, communication, mobility, self-care, recreation and leisure.

What next?

The list of aspects of health that professionals target contributes to a vision of what health services might seek to achieve.

The targets of health professionals can be compared with the [aspects of health families say are important](#).

We need to promote discussion and agreement between professionals and families professionals on the key outcomes for children and young people with neurodisability. Then we need to find ways to measure and monitor these outcomes.

Professionals say health care should focus on improving physical and social functioning. However, they seem to think health services are less responsible for social outcomes. Do health professionals need to rethink what they can do?

Who reviewed our research to make sure it was done well?

This study is published in a journal called Archives of Diseases in Childhood. Before the journal accepted the study to be published it asked independent experts to look at the paper and decide whether it had been properly carried out and whether it was important enough to publish.

The full version of the research paper is published in [Archives of Diseases in Childhood](#).

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

The team that carried out the research are: Chris Morris, Astrid Janssens, Richard Tomlinson, Jane Williams and Stuart Logan with support from four parent members from the PenCRU Family Faculty.

Chris, Astrid and Stuart are all part of the Peninsula Cerebra Research Unit and the NIHR Collaboration for Leadership in Applied Health Research and Care of the South West Peninsula (PenCLAHRC) at the University of Exeter Medical School. Richard is a paediatrician at Royal Devon and Exeter NHS Foundation Trust (Department of Child Health) and Jane is a paediatrician at Nottingham University Hospitals NHS Trust.

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