

Development of a parent-reported communication outcome measure for non-speaking children with neurodisability

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This research was supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration Kent, Surrey, Sussex. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care

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Introduction

Background: Approximately 25% of children with neurodisability are non-speaking^{1, 2}. Tools are lacking to demonstrate the effect of interventions for this population. The development of a parent-reported outcome measure will help speech and language therapists (SLTs) reliably identify whether specific therapy approaches have led to changes in a child's communication over time and support evidence-based practice.

Aim: This study aims to understand the views of UK parents and SLTs about which communication changes they think are important when measuring the progress of children (aged 4 to 18 years) who use methods other than speech to communicate.

Methods

1. Literature review

- Qualitative meta-Synthesis³
- Thematic data synthesis⁴
- Identified need for primary research on valued communication outcomes

2. Item generation

- Semi-structured interviews with 26 parents
- Focus groups with 14 SLTs
- Framework approach⁵

3. Item development

- Delphi study⁶
- Two survey rounds
- Consensus meeting with parents and SLTs

Interview and focus group themes

Child's skills

- What a child is able to and not able to communicate
- Changes to a child's communication
- Impact of communication difficulty on quality of life

'It's frustrating for her because she knows what she wants and we have to guess' (parent of a child with CP, age 8)

Goals for child

- Views on different types of communication
- Short term goals for child
- Participation and independence goals
- Longer term aspirations

'Just to be able to tell me his wants, his needs and if he's in pain or not' (parent of an autistic child, age 10)

Outcome measures

- Process for measuring communication changes
- Current Issues with outcome measurement
- Ideas on how communication could be measured

'We found that current measures are not sensitive enough to identify change within the group that we're working with' (SLT)

Future Plans

- Analysis of Delphi study data and refine items
- Cognitive interviews (pre-testing of items)
- Assessment of psychometric properties
- Final Selection of items for the outcome measure

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