

Informing the NHS Outcomes Framework: evaluating meaningful health outcomes for children with neurodisability using multiple methods including systematic review, qualitative research, Delphi survey and consensus meeting

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Plain English summary

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This research sought agreement on what children and young people with neurodisability want from their health care, and what clinicians are aiming to achieve. We spoke to 54 children and young people with neurodisability, and to an unrelated group of 53 parents in focus groups and interviews. We also engaged with over 200 health professionals in several rounds of an online survey. A small group of 15 young people, parents and professionals who had participated in the research then met to rank the most important outcomes. The key health outcomes were agreed as communication, emotional well-being, pain, mobility, independence/self-care, worry/mental health, social activities and sleep. Parents of children with learning disability also rated behaviour, toileting and safety as important. NHS performance is increasingly being judged using questionnaires called patient-reported outcome measures, or PROMs. Therefore, we assessed whether or not the key outcomes we identified could be measured reliably using existing PROM questionnaires. No PROM was found to be entirely satisfactory in scientific terms but some showed potential. Few PROMs had been tested specifically with children and young people affected by neurodisability. Young people and parents reacted unfavourably to examples of the questionnaires we showed them in our research. Agreement between parents and young people's responses to these questionnaires is generally not reliable. However, the views of parents are crucial, particularly for children who cannot respond themselves. Further consultation with young people, families and professionals is warranted to support using PROMs to measure NHS outcomes. Research to test potential PROMs with different age groups and conditions would be valuable.

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