

Research Summary

Top 10 research topics on interventions for children and young people with neurodisability

Key messages

- The British Academy of Childhood Disability-James Lind Alliance Research Priority-Setting Partnership brought together young people, parent carers and clinicians. The aim was to agree a Top 10 topics for research evaluating interventions that could improve health and wellbeing.
- The top 3 research priorities related to (i) establishing the optimal frequency and intensity (dose) for mainstream therapies, (ii) means for selecting and encouraging use of communication strategies, (iii) ways to improve children's attitudes towards disability.
- The Top 10 included evaluating interventions to promote mobility, self-efficacy, mental health, continence, physical fitness, educational inclusion, and reduce impacts of sleep disturbance.

The [British Academy of Childhood Disability](#) (BACD) is a UK organisation for professionals working with children and young people with [neurodisability](#).

The [James Lind Alliance](#) (JLA) supports patients, carers and clinicians to agree the most important treatment uncertainties for particular health conditions.

Who carried out this research and why?

BACD established a JLA Research Priority Setting Partnership (PSP) focusing on neurodisability and provided funding. The Steering Group included 2 members from the [National Network of Parent Carer Forums](#) (NNPCF), a young adult and a charity representative from the [Council for Disabled Children](#) (CDC), a paediatrician, a researcher (with experience as an allied health professional), the editor of the [UK Database of Uncertainties about the Effects of Treatments](#) (UK DUETs), and was chaired by a JLA advisor.

The project was led by the team at Peninsula Cerebra Research Unit (PenCRU), a childhood disability research unit at the University of Exeter Medical School.

Patients and carers are key users of research findings but their views on which topics should be investigated are under-represented. The JLA has a method to empower patients and carers and non-research clinicians to decide research priorities. BACD applied this method in childhood neurodisability in the UK.

The BACD-JLA Research Priority Setting Partnership brought together young people, parent carers and clinicians as equal partners. The aim was to agree a top 10 topics for research for children with neurodisability. BACD defined the topics as having to be about "ways to improve the health and/or wellbeing of children and young people with neurodisability".

What did we do?

We invited relevant charities supporting children and families, and societies and special interest groups for

clinicians to become partners in the project. There were 13 charities and 8 professional societies who became partners, listed on [the project website](#).

An open survey was conducted to gather ideas for potential research topics from families and clinicians. 369 people submitted one or more suggestions (40% were not clinicians). We received 809 suggestions in total. We also checked research recommendations from organisations that review evidence (e.g. National Institute for Health and Care Excellence, or NICE).

The suggestions were checked to see if they were in the remit of the project:

- Was there an identifiable intervention?
- Was it something that would potentially improve children's health and wellbeing?
- Could the health outcome be measured?

The Steering Group identified 356 suggestions that were within the remit of the project. We reduced this list to 57 items by merging similar issues. All were confirmed as uncertain from research findings.

The 57 topics identified were further prioritised by partner organisations and survey respondents. 75 people participated via email and post in the initial prioritisation survey (26 parents, one young person, 10 charity representatives and 39 clinicians). This process created a shortlist of 25 topics.

The final stage was a one-day workshop to decide the final priority ranking and top 10 topics. Participants in the workshop came from various regions of England: there were 3 young adults with neurodisability, 7 parent carers, 3 representatives from charities, a disability advisor in education, and 8 health professionals – paediatrician, speech and language therapist, three physiotherapists, occupational therapist, nurse, orthopaedic surgeon. The meeting involved several facilitated small group discussions and then all together as a single group. The research topics were printed on cards so that they could be ordered and reordered at various stages in the small and large group discussions.

What did we find?

At the end of the final workshop the participants agreed a rank order for [the top 10 and all 25 topics](#). We also published [a second press release about the top 10 with links to entries in the UK DUETs database](#). The top 10 is also printed on the next page.

We found that the areas that came into the Top 10 were practical aspects of services and care that affect the lives of children, young people and families day to day. We also found there is much in common in the research questions that matters across all children and young people with neurodisability including therapies, mobility and schools.

Limitations to these findings

Although we successfully engaged with families and professionals to identify and select topics, there are several limitations to the project.

- Not all the suggestions were about things that might be done (interventions), so some ideas could not be used in this project.
- We struggled to get ideas from children and young people in the survey.
- The topics are broad because of the way they were brought together. This means that most topics need refinement to take forward.
- Because we grouped any condition that was a neurodisability we will have missed many topics that are specific to particular conditions.
- The top 10 is a result of the systematic and transparent process that was followed, but might produce a different rank order if different people and organisations took part.

What next?

The National Institute for Health Research (NIHR) is the main Government organisation that funds health related research in the UK. The NIHR has been very engaged with the project and will use the priorities to consider commissioning research.

This project is now completed. However we continue to publicise the top 10 and other topics that were identified to researchers and organisations that fund research, such as the NIHR and charities.

Who reviewed our research?

The academic paper describing the project is published in a journal called *BMJ Open*. Before the journal accepted the paper to be published the editor asked independent academics to look at the paper and decide whether the research had been carried out properly, reported clearly, and whether it was important enough to publish.

TOP 10 'SHARED PRIORITY' RESEARCH QUESTIONS FOR CHILDREN AND YOUNG PEOPLE WITH NEURODISABILITY

1. Does the timing and intensity of therapies (e.g. physical, occupational and speech and language therapy, 'early intervention', providing information etc.) alter the effectiveness of therapies for infants and young children with neurodisability, including those without specific diagnosis? What is the appropriate age of onset/strategies/ dosage/ direction of therapy interventions?
2. To improve communication for children and young people with neurodisability: (a) what is the best way to select the most appropriate communication strategies? And (b) how to encourage staff/carers to use these strategies to enable communication?
3. Are child-centred strategies to improve children's (i.e. peers) attitudes towards disability (e.g. buddy or Circle of Friends etc) effective to improve inclusion and participation within educational, social and community settings?
4. Does appropriate provision of wheelchairs to enable independent mobility for very young children improve their self-efficacy?
5. Are counselling/psychological strategies (e.g. talking therapies) effective to promote the mental health of children and young people with neurodisability?
6. What is the (long term) comparative safety and effectiveness of medical and surgical spasticity management techniques (Botulinum neurotoxin A (BoNTA), Selective Dorsal Rhizotomy (SDR), Intrathecal Baclofen (ITB), orally administered medicines) in children and young people with neurodisability?
7. Does a structured training programme, medicines and/or surgery speed up the achievement of continence (either/or faecal or urinary) for children and young people with neurodisability?
8. What strategies are effective to improve engagement in physical activity (to improve fitness, reduce obesity etc.) for children and young people with neurodisability?
9. Which school characteristics (e.g. policies, attitudes of staff etc.) are most effective to promote inclusion of children and young people with neurodisability in education and after-school clubs?
10. What is the long term safety, effectiveness and sustainability of behavioural strategies and/or drugs (e.g. melatonin) to manage sleep disturbance in children and young people with neurodisability (outcomes include time to onset, duration, and reducing impact on family)?

The full version of the academic paper is published in the journal [BMJOpen](#) and freely available. If you have difficulty obtaining a copy then please contact pencru@exeter.ac.uk

The research team are a collaboration between the British Academy of Childhood, National Network of Parent Carer Forums, Council for Disabled Children, UK Database of Uncertainties about the Effects of Treatments, James Lind Alliance. The study was led by PenCRU at the University of Exeter.

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