

JLA Research Priority Setting Partnership

The aim of the JLA Childhood Disability Research Priority Setting Partnership was to identify and prioritise unanswered questions about the effectiveness of interventions for children and young people with neurodisability from patient, carer and clinical perspectives.

A wide range of professional and family organisations were contacted and many signed up as partners in the project. Suggestions were gathered in an open survey that was advertised widely by partners. The suggested topics were aggregated and framed as research questions, then checked against existing systematic reviews of research evidence to ensure they were unanswered.

The topics were initially prioritised in a preliminary vote with partner organisations and survey participants, and then discussed and rank ordered by a group of young people, parent carers and clinicians at a one-day workshop held at the RCPCH.

The Top 10 represents the 'shared priority' topics selected by participants at the workshop. We have also made available the topics ranked 11-25 and all the issues identified in the survey through the [BACD website](http://www.bacd.org.uk).

These data are catalogued in the [UK Database of Uncertainties about the Effects of Treatments \(UK DUETs\)](#). If you are reading an electronic version, you can click on the question opposite to link directly to the entry in UK DUETs. This enables you to see the original submissions to the survey, and references to relevant systematic reviews of the evidence.

The JLA process produces broad research topics that represent the issues identified. To design research studies to address the priorities, interventions and comparators, target populations and outcome measures would need to be carefully defined.

The project has gained considerable interest from the NIHR and, as well as identifying priority topics, it has raised the profile of childhood neurodisability generally with the main UK government agency that fund health research.

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TOP 10 'SHARED PRIORITY' RESEARCH QUESTIONS

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 (BoNT-A), 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)?



Workshop participants holding up the cards of the Top 10 Priorities