

JLA Childhood Disability Research Priority Setting Partnership

23 June 2014

The aim of the Childhood Disability Research Priority Setting Partnership was to identify unanswered questions about the effectiveness of interventions for children and young people with neurodisability from patient, carer and clinical perspectives. Then, to prioritise the questions that young people, parent carers and clinicians agree as most important as research topics.

Suggestions were gathered in an open survey, 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 vote with stakeholders, and subsequently discussed at a workshop attended by young people, parent carers and various clinicians.

The Top 10 represents the 'shared priority' topics selected by participants at the workshop. We are also making available the topics ranked 11-25 and all the issues identified in the survey. These questions have also be entered in to [UK DUETs](#)

The uncertainties raised and prioritised are the outcome of a systematic and transparent process that includes stakeholders that have often not had a say in setting the research agenda. The Top 10 'shared priorities' for research, and other topics identified, are a resource to inform government and charitable agencies that commission and fund research.

Notes

[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 or 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 disturbances of movement, cognition, hearing and vision, communication, emotion and behaviour.

Interventions, therapy or procedures were any environmental factor in the World Health Organization [International Classification of Functioning Disability and Health](#).

There was an expectation that, if shown to be effective in research, the intervention could be expected to benefit the health and wellbeing of children with neurodisability within 3-5 years of the results demonstrating effectiveness.

The Steering Group included a young adult, two parent carers, a paediatrician, a charity representative, a researcher, and was chaired by a JLA advisor.

For more information on the [JLA Childhood Disability Research Priority Setting Partnership](#)

For information about the [James Lind Alliance](#)

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The Top 10 'shared priority' research questions

Rank	Research question indicative of topics suggested in survey
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)?

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Other research questions considered at the priority setting workshop in ranked order

11	What is the safety and effectiveness of drugs compared to talking therapies (e.g. Cognitive Behavioural Therapy) to treat anxiety in children and young people with Autistic Spectrum Disorders?
12	Are any types of physical therapy (e.g. Bobath, Neuro-Developmental Therapy, conductive education, hydro, constraint, strength-training etc) more or less effective to promote motor functioning in children and young people with neurodisability (e.g. cerebral palsy, acquired brain injury)?
13	Are sensory processing/integration therapeutic programmes effective in improving behaviour and/or increasing play/participation for children and young people with neurodisability?
14	Are behavioural and sensory interventions (e.g. early intensive behavioural intervention, EarlyBird, encouraging socialisation with peers etc.) effective in managing symptoms of Autistic Spectrum Disorder?
15	Are postural management programmes (using standing frames and sleep systems etc) effective and cost effective to prevent deformity (hip and/or spine) and improve function in children and young people with neurodisability? What is the incidence of adverse effects e.g. pain, sleep problems etc.?
16	Are child-focused strategies (e.g. one-to-one or group social and skills training) effective to improve confidence, self-esteem and promote participation in recreation and leisure activities for children and young people with neurodisability?
17	Do cross-sector interventions (e.g. key workers, named contacts to promote integrated health, social care, education) improve school attendance, reduce admissions, and parents' satisfaction and experience of care for children and young people with neurodisability?
18	Does promoting public positive attitudes towards disability improve participation in recreation and leisure activities for children and young people with neurodisability?
19	Are dietary modifications/restrictions (e.g. gluten, casein, dairy, meat etc.) effective in managing symptoms of Autistic Spectrum Disorder?
20	Are oro-motor treatment strategies (e.g. oral motor exercises, sensory stimulation, sensorimotor activities etc.) effective to improve eating and drinking or speech for children and young people with neurodisability? Are there identifiable subgroups that benefit more from the strategies?

21	Are any designs of orthoses (e.g. Lycra, kinesiotaping, plastic etc.) more or less effective to promote functioning and prevent deformity for children and young people with neurodisability?
22	Are interventions to improve consistency of approach between health and education agencies (e.g. keyworkers) effective to improve behavioural problems in children with Autistic Spectrum Disorder (ASD)?
23	What is the long term safety and effectiveness of drugs used in seizure management, especially in terms of adverse effects on learning, psychosis, anxiety, anger and rage?
24	Does using instrumented gait analysis improve decision-making about treatments compared to clinical assessment alone for children and young people with cerebral palsy?
25	Do massage-based therapies improve functioning and wellbeing for children and young people with neurodisability?

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Other questions identified in the survey not selected for the priority setting workshop, in rank order of rating from the interim prioritisation survey

26	Does chiropracty improve gross/fine motor function of children with hemiplegia?
27	Is horse riding an effective therapy to improve functioning and promote wellbeing in children and young people with neurodisability?
28	Would education in self-management (e.g. of physical problems associated with cerebral palsy) improve the quality of life and socio-economic independence of young adults with neurodisability?
29	Does trampolining improve balance and coordination (motor function) in children and young people with neurodisability?
30	Are computer games an effective mode of therapy for children and young people with neurodisability to improve physical and/or social functioning?
31	Do nutritional supplements (e.g. omegas 3,6,9) reduce symptoms and improve functioning of children with Autistic Spectrum Disorder?
32	What advice regarding personal dental care (e.g. brushing, flossing, swilling etc.) should be given to families of children and young people with neurodisability to maintain oral health?
33	Would personalised systems (e.g. handheld or online electronic resources) to educate family/staff/carers about correct fitting of orthoses reduce adverse complications and improve adherence for children and young people with neurodisability?
34	Is ongoing (6 months) rhythm therapy (e.g. by drumming or Interactive Metronome or dancing) effective to improve handwriting and other functioning in children and adults with Developmental Coordination Disorder (particularly the more mild form) or dyspraxia?
35	Is a small dose of stimulant medication helpful in children with Autistic Spectrum Disorder (ASD) and learning disability to reduce hyperactive behaviours?
36	Does nutritional supplementation with vitamin D improve motor function in children and young people with neurodisability?
37	Is taking aspirin beneficial (e.g. to reduce recurrence) for a child who has had a stroke with no known cause?
38	What is the (long term) safety and effectiveness of psychostimulant drug management (including co-prescriptions) for Attention Deficit Hyperactivity Disorder (ADHD)? Does the psychostimulant maintain effectiveness in the long term and/or are there problems associated with discontinuation?
39	Does the diet (formula versus blended food) administered through gastrostomy influence nutrition and Quality of Life, and improve digestive functioning (reduce reflex, constipation etc.) in children and young people with neurodisability who have had gastrostomy and use enteral feeding?
40	Does use of enteral peg feeding by young children with neurodisability with or without speech and language therapy impact on their ability to develop useful vocal communication skills?

41	Would teaching body awareness techniques early (The Alexander Technique, yoga etc.) improve postural/sensory awareness (e.g. bladder control) for children and young people with neurodisability?
42	Does screening and following recommended best practice (e.g. orthotics, postural management, and surgery) reduce hip dislocation/scoliosis in children with cerebral palsy?
43	Do seizure alarms for children with epilepsy reduce Sudden Unexpected Death in Epilepsy (SUDEPS) / improve seizure management/reduce parent stress?
44	Are chest physiotherapy techniques and/or assistive technologies (e.g. PEP) effective to reduce mortality/chest infections/Quality of Life for children and young people with respiratory impairments associated with neurodisability
45	Does multilevel surgery improve Quality of Life of children and young people with cerebral palsy?
46	Is cycling an effective strategy for reducing hip dislocation in children and young people with cerebral palsy?
47	What is the effectiveness and cost effectiveness of housing adaptations in terms of improving health and social outcomes for disabled children and families?
48	Is there a group of children and young people with neurodisability for whom a low stimulation ward environment would substantially reduce the duration of inpatient episodes?
49	Is drug therapy (trihexyphenidyl) effective to control drooling for children and young people with neurodisability?
50	Is provision of special glasses (e.g. with tinted, ambient prism lenses) and 'vision therapy' effective to improve functioning in children and young people with neurodisability?
51	Are light therapies effective to manage sleep/improve daytime functioning (learning) for children and young people with neurodisability?
52	Is joint fusion more effective than joint preserving approaches in managing ankle foot deformities in children and young people with neurodisability?
53	Are any designs of hearing aids (e.g. Edulink and others) more or less effective in children and young people with auditory neuropathy and/or auditory processing disorder?