

Partnership launched to prioritize research for 'neurodisabled' children

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A ground breaking new project has been launched to find out what research is important to children and young people with neurodisability, their families, and the healthcare professionals who work with them. This is a unique opportunity for the consumers of neurodisability research to have their say and influence the research agenda.

A UK-wide partnership comprising experts in childhood neurodisability and related issues, the James Lind Alliance Childhood Disability Research Priority Setting Partnership will identify the questions which remain unanswered about the effectiveness of treatments. It will take into account the views of young people, their families and the [clinicians](#) who care for them. It will then prioritise the unanswered questions into a 'Top 10' list of topics for research which will be taken to research commissioning bodies to be considered for funding.

Similar exercises conducted in other health areas have given patients a real influence over what research is prioritised by funding bodies.

Steering Group member Mary Busk said: "As the mother of a child with a neurodisability who has really struggled to get diagnoses and essential [health services](#) for her child, it is vitally important that research for [children](#) with neurodisabilities becomes high profile. I can see firsthand that many therapies, procedures and treatments are central to my son's health, development, quality of life and his future prospects. Research needs to be relevant to our children and young people's lives and to inform more clearly decisions about the importance of investment in

health services for neurodisabled children."

The care of children with neurodisability is a complex field, and there is uncertainty about the effectiveness of many of the therapies, procedures and treatments employed to care for them. Neurodisability incorporates a wide range of conditions including [cerebral palsy](#), intellectual disorders, [autism](#) and [epilepsy](#).

Chris Morris, Senior Research Fellow at the University of Exeter, said: "We need to be certain that the methods we use to treat and care for children with neurodisability are effective and are true to our patients and their families. The best way to do this is to use the collective knowledge of such children, their families and the people who care for them to set the agenda for future research in this area, so that it in turn provides evidence about effective treatments, procedures and therapies. The James Lind Alliance Childhood Disability Research Priority Setting Partnership will help us to achieve this aim."

More information: To find out more or to get involved, go to bacdis.org.uk/research/psp.htm

What is 'neurodisability'?

Neurodisability includes a group of chronic conditions with a broad range of severity and complexity, some of which can vary over time. Neurodisability is a consequence of impairment of the brain, central or peripheral nervous system that creates activity limitations. This may result in physical difficulties (such as cerebral palsy), learning difficulties (such as intellectual disorders), and social/communication difficulties (such as in autism), or other medical conditions (such as the problems associated with epilepsy). Sensory, behavioural and emotional difficulties are all included if they are a consequence of neurological impairment. Some children affected by neurodisability are diagnosed

with specific syndromes and conditions, whilst others are not given a named diagnosis.

Provided by University of Plymouth

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