

Community Priorities for Research on Neurodevelopmental Disorders

JLA PSP final report (2018)

<https://www.jla.nihr.ac.uk/priority-setting-partnerships/neurodevelopmental-disorders-canada/downloads/Neurodevelopmental-Disorders-Canada-Final-Report.pdf>

For which topic were research priorities identified?

neurodevelopmental disorders

In which location was the research priority setting conducted?

North America - Canada

Why was it conducted at all?

People living with neurodevelopmental disorders and those who support them have an inherent understanding of the needs they face and their input on research priorities would truly enrich the research questions being asked. As well, research on one neurodevelopmental disorder is often done in isolation of research on other disorders. Yet there is overlap in the biology, presentation, and needs of the respective communities. We believe that research across neurodevelopmental disorders may help us better understand these conditions.

What was the objective?

to identify questions and priorities that have not yet been addressed by the research community

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

February 2016 - September 2017

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: steering group established, scope defined. Step 2: gathering questions: survey to gather questions or uncertainties from community about treatment/interventions for neurodevelopmental disorders, total of 1264 questions submitted. Step 3: data processing: out-of-scope removed, the remaining 898 questions then grouped into 64 summary questions, summary questions checked against published research, 63 summary questions remained. Step 4: interim ranking: survey asking community to choose and rank the 10 questions most important to them from the list of 63, top 20 ranked questions brought forward, rankings also considered for each of the two stakeholder groups, 10 highest ranked questions from each group almost all found within top 20 ranked questions. Step 5: final prioritization: workshop: each question discussed and ranking of each question debated

Which stakeholders took part?

People living with neurodevelopmental disorders, their families, people who regularly look after people with neurodevelopmental disorders (carers), and health/education professionals. Survey: 258 participants: 184 people having lived experience with neurodevelopmental disorders or who completed the survey on behalf of someone with lived experience, 139 people having professional experience with neurodevelopmental disorders. Interim ranking: 177 participants. Workshop: 31 participants: 17 with lived experience (including those from ASD, ID, ADHD, Fragile X, and Rett Syndrome communities) and 14 participants with professional experience (including a paediatric neurologist, early childhood educator, clinical psychologist, and service provider).

How were stakeholders recruited?

No information provided.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group. The steering group consisted of 8 members: clinicians and patient advocates. The members were responsible for overseeing and guiding the process, defined the scope, were involved in data processing and ensured balance of perspectives in the workshop.