

A Canadian First Facilitated by Ontario Brain Institute, in Collaboration with the POND Network

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BACKGROUND

- People living with neurodevelopmental disorders and those who support them have an inherent understanding of the needs they face and their input would truly enrich the research being done.
- By engaging stakeholders at various stages of the research process, researchers hope to improve the quality and outcomes of research, making research more relevant and impactful to those for whom it concerns.
- The James Lind Alliance is a United Kingdom-based initiative that has created a standardized methodology to address the imbalance in the research decision making through joint research priority setting.
- Ontario Brain Institute and associated stakeholders from the Province of Ontario Neurodevelopmental Disorder (POND) Network partnered with the James Lind Alliance to identify unanswered research priorities across neurodevelopmental disorders.

OBJECTIVE

- Identify research priorities from a wide range of stakeholders in neurodevelopmental disorders that have not yet been addressed by the research community.

RESULTS

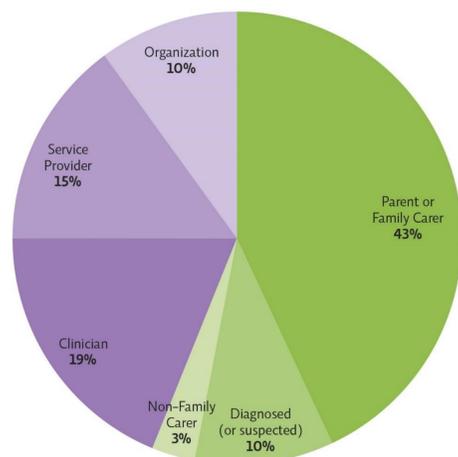


Figure 1. Respondent Experience.

- There was a good balance between respondents with lived experience vs. work experience in neurodevelopmental disorders.
- 184 had lived experience or completed a survey on behalf of someone with lived experience.
- 139 identified as having professional experience with neurodevelopmental disorders.
- Over 35 neurodevelopmental disorders represented, including 93 from Autism Spectrum Disorder and 56 from Attention Deficit Hyperactivity Disorder.
- “Other” category includes other genetic syndromes related to intellectual disability and/or comorbidities identified by respondents.

RESULTS



These are the Top 10 priorities for neurodevelopmental disorders:

1. What are the most effective treatment options/plans (e.g., timing, frequency, duration, type, intensity or dosage) for individuals with neurodevelopmental disorders for both short and long-term benefits?
2. How can system navigation be organized in a manner that enables coordinated services and supports across the lifespan for individuals with neurodevelopmental disorders and their families?
3. Which biological treatments (including medications, gene therapy, stem cell therapy, etc.) are effective for neurodevelopmental disorders and associated symptoms?
4. Which child and family-centered interventions or approaches promote optimal individual and family functioning?
5. Which interventions best help individuals with neurodevelopmental disorders develop emotional and behavioural regulation (including increasing impulse control and reducing compulsive behaviour)?
6. Which resources are needed to more effectively address the health, social and emotional needs of families or caregivers of individuals with neurodevelopmental disorders?
7. How can treatment decisions for individuals with neurodevelopmental disorders be more precise (i.e., based on the diagnosis, age, functional need of the individual)?
8. Which are the most effective pharmacological and non-pharmacological treatments for aggressive and self-injurious behaviour in individuals with neurodevelopmental disorders?
9. Which are the most effective pharmacological and non-pharmacological intervention(s) to reduce anxiety in individuals with neurodevelopmental disorders?
10. Which interventions are most effective to help individuals with neurodevelopmental disorders improve their social skills and develop and maintain social relationships?

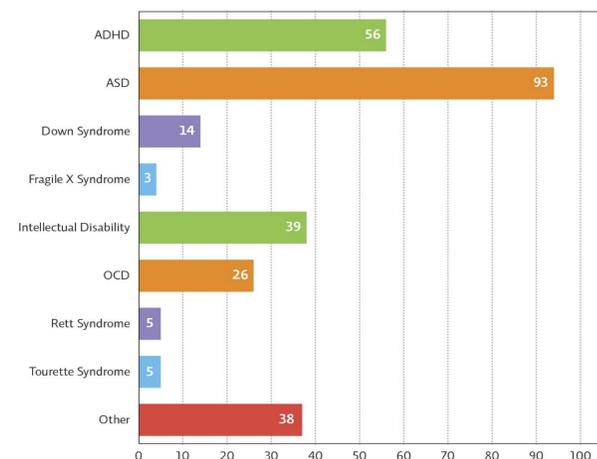


Figure 2. Neurodevelopmental Disorder Diagnosis.

FUTURE DIRECTIONS

- We hope these priorities will be shared broadly and be used to drive the direction of future neurodevelopmental disorder research.
- If you are working on one of these priorities or want to help advocate for these stakeholder-driven priorities, email us: prioritysetting@braininstitute.ca or visit: www.braininstitute.ca
- For further information about the Neurodevelopmental Disorder Priority Setting Partnership, including our soon to be released plain language report and public data release, please visit: www.braininstitute.ca/nddpriorities